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A Good Death: End-of-Life Lawyering Through a Relational Autonomy Lens

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A GOOD DEATH: END-OF-LIFE LAWYERING THROUGH A RELATIONAL AUTONOMY LENS

Genevieve Mann*

Abstract: Death is difficult—even for lawyers who counsel clients on end-of-life planning. The predominant approach to counseling clients about death relies too heavily on traditional notions of personal autonomy and a nearly impenetrable right to be free from interference by others. Rooted in these notions, contracts called “advance directives” emerged as the primary tool for choosing one’s final destiny. Nevertheless, advance directives are underutilized and ineffective because many people are mired in death anxiety, indecision, and the weight of planning for a hypothetical illness. In the end, many do not get the death they choose: to trust in others and share the arduous decision-making responsibility with loved ones.

This Article proposes that lawyers shift away from a rights-based paradigm that insists clients make decisions alone, unobstructed by family and friends. Instead, it offers an alternative counseling model that draws on relational autonomy and values the inherent interplay between client independence and interdependence. Grounded in feminism, relational autonomy reimagines individualistic conceptions of self and identity to embrace our essential social and connected nature. Lawyers can enhance end-of-life decision-making to be in alignment with client goals by refocusing it from a solitary experience to one inclusive of the interests and participation of loved ones. While death is inevitable, we no longer need to insist it is done alone.

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INTRODUCTION

*“Endings matter, not just for the person but, perhaps even more, for the ones left behind.”*¹

Many recall the agonizing case of Nancy Cruzan: a young woman injured in a car accident that left her in a permanent vegetative state for eight years before she was allowed to die.² While the case gripped national attention and established end-of-life jurisprudence, most do not know the secondary tragedy of that case—the suicide of her father, Joseph Cruzan.³ For nearly seven years, he doggedly advocated for his incapacitated daughter to be removed from life-sustaining treatment, finally succeeding after new evidence emerged of her stated desires.⁴ While at first

1. ATUL GAWANDE, BEING MORTAL: ILLNESS, MEDICINE, AND WHAT MATTERS IN THE END 252 (2014).

2. Tamar Lewin, *Nancy Cruzan Dies, Outlived by a Debate Over the Right to Die*, N.Y. TIMES (Dec. 27, 1990), <https://www.nytimes.com/1990/12/27/us/nancy-cruzan-dies-outlived-by-a-debate-over-the-right-to-die.html> (last visited Nov. 2, 2023).

3. WILLIAM H. COLBY, LONG GOODBYE: THE DEATHS OF NANCY CRUZAN 393 (2002).

4. *Id.* at 322, 386–87; *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 283–85 (1990). The Supreme Court held that it was permissible for Missouri to require evidence of an incompetent

Mr. Cruzan seemed “at ease” that Nancy was allowed to die, in the years that followed he became increasingly despondent and clinically depressed.⁵ Some speculated Mr. Cruzan’s severe depression and subsequent suicide were the result of having to decide to end the life of his daughter.⁶ But what if it was the result of years of being ignored, criticized, and vilified for his absolute certainty that his daughter would not want to be kept alive in an incapacitated state? As the case wound its way to the United States Supreme Court, the family was subjected to hate mail and agonizing judgment, with people questioning whether they were attempting to “euthanize” their disabled daughter.⁷ After years of litigation and media scrutiny, while Nancy lay peacefully dying, her family faced protesters camped outside the hospital.⁸

The lawyer for the Cruzan family, who also authored a book about the case, wrote, “Joe always said that the decision to withdraw the tube from Nancy was one of the few things in life that he was truly sure of.”⁹ The Supreme Court refused to consider evidence from the family regarding her wishes, stating “there is no automatic assurance that the view of close family members will necessarily be the same as the patient’s would have been had she been confronted with the prospect of her situation while competent.”¹⁰ This “autonomy ideal” has long served as the sole guiding force in end-of-life decision-making.¹¹

Traditional autonomy—the right to self-governance and freedom from bodily intrusion—is the foundation of end-of-life jurisprudence.¹² To protect this underlying liberty-based interest, the controlling principle of end-of-life planning law is to uphold the right of self-determination.¹³ Medical providers and lawyers alike seek to guard an individual’s

person’s wishes regarding whether to withdraw life-sustaining treatment to be proved by clear and convincing evidence. *Id.* Although the Court found the Cruzans did not meet that standard, a new witness ultimately provided evidence that Nancy would not have wanted to remain alive by artificial means, and her feeding tube was removed. *Id.*

5. COLBY, *supra* note 3, at 392.

6. *Id.* at 392–94.

7. *Id.* at 221–23. This included media statements such as the one made by a nurse: “The Humane Society won’t let you starve your dog.” *Id.* at 363.

8. *Id.* at 369; Lewin, *supra* note 2. There was even a failed attempt by a small religious group to remove Nancy Cruzan from the hospital to re-attach the feeding tube. COLBY, *supra* note 3, at 369.

9. COLBY, *supra* note 3, at 394.

10. *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 286 (1990).

11. See Robert A. Burt, *The End of Autonomy*, HASTINGS CTR. REP. (SPECIAL REP.), Nov.–Dec. 2005, at S9, S9.

12. See Susan Adler Channick, *The Myth of Autonomy at the End-of-Life: Questioning the Paradigm of Rights*, 44 VILL. L. REV. 577, 581 (1999).

13. See Lois Shepherd, *The End of End-of-Life Law*, 92 N.C. L. REV. 1693, 1697 (2014).

absolute control over planning for death insulated from consideration of their relationships with others. The default rule regards protection of a person's singular right to make end-of-life decisions as empowerment.¹⁴ The corollary is that the influence of others impedes autonomous decision-making. As lawyers have been trained to counsel clients using this traditional autonomy model,¹⁵ current best practice demands that the client's decision-making process, and death itself, be a solitary one.

While it has long been true that a patient with capacity has the right to choose life-sustaining treatment, or refuse it, the matter was less clear for incapacitated patients who could not guide medical decisions.¹⁶ Protecting the sacrosanct right to self-determination seemed impossible. How can a court uphold an unassailable right when the person is unable to express it? Steeped in this individual privacy right, courts struggled, rudderless, and relied on autonomy as a guiding principle.¹⁷ The advance directive—a legal document outlining a person's end-of-life medical choices—became the tool to uphold and value individual autonomy in the absence of capacity.¹⁸ If a person contemplated and documented treatment choices prior to incapacity, the advance directive could direct treatment and preserve a person's wishes.¹⁹

Despite decades of policy and education initiatives to encourage completion of advance directives, they remain underutilized.²⁰ Academics have cited poor drafting, client resistance, and provider reluctance as reasons why advance directives have failed.²¹ There have been various attempts to salvage advance directives and increase their use through innovative projects.²² As an adjacent response, the medical field embraced

14. See Michael R. Flick, *The Due Process of Dying*, 79 CALIF. L. REV. 1121, 1129–30 (1991).

15. See Lorraine M. Bellard, *Restraining the Paternalism of Attorneys and Families in End-of-Life Decision-Making While Recognizing that Patients Want More than Just Autonomy*, 14 GEO. J. LEGAL ETHICS 803 (2001).

16. Shepherd, *supra* note 13, at 1699.

17. See Janet L. Dolgin, *Dying Discourse: Contextualizing Advance Care Planning*, 34 QUINNIPIAC L. REV. 235, 253–65 (2016).

18. Charles P. Sabatino, *The Evolution of Health Care Advance Planning Law and Policy*, 88 MILBANK Q. 211, 212 (2010) [hereinafter Sabatino, *Evolution*].

19. *Id.*

20. See Dolgin, *supra* note 17, at 247.

21. T.P. Gallanis, *Write and Wrong: Rethinking the Way We Communicate Health-Care Decisions*, 31 CONN. L. REV. 1015, 1025–29 (1999); Dorothy D. Nachman, *Living Wills: Is It Time to Pull the Plug?*, 18 ELDER L.J. 289, 316–17 (2011); *Barriers to Universal Advance Directives*, 40 BIFOCAL 69, 69–70 (2019).

22. See, e.g., Dolgin, *supra* note 17, at 283–87 (discussing the examples of “Respecting Choices,” a Wisconsin multi-disciplinary outreach program designed to educate the community about medical choices at the end of life, and Conversations: Health and Treatment (CHAT), a model designed to

Advance Care Planning—an ongoing, supportive process that incorporates personal values, life goals, and preferences into medical care decisions.²³ Some healthcare providers anticipated that it would improve end-of-life care and empower individuals in autonomous decision-making.²⁴ Instead, these efforts have been disappointingly ineffective at improving outcomes and ensuring that patient care accords with an individual’s preferences.²⁵

This Article argues that the failure of advance directives, and the unsuccessful attempts to improve end-of-life care, are the result of the legal community’s strict adherence to the traditional autonomy framework. The exclusion of loved ones does not serve dying patients or clients preparing for death. The rigid structure, which assumes that individuals prefer to make these intimate and private decisions alone, conflicts with stated patient preferences.²⁶ Lawyers promise clients that advance directives will ensure the care they want and unburden loved ones, when “the reality is that we’ve been pushing a myth.”²⁷ Many dying patients prefer to include their loved ones in the dying decision-making process.²⁸

Instead of clinging to traditional notions of autonomy, this Article advances the argument that end-of-life planning should be viewed through a relational autonomy lens. Rather than an outright rejection of traditional autonomy, relational autonomy views the individual “in an ongoing, dynamic way by the relationships through which each person interacts with others.”²⁹ This does not dismiss established concepts of self-determination and independence, but instead holds that interdependence enhances selfhood and individual rights.³⁰ Autonomy has been restricted

provide education, encourage “chats” about advance care planning, and provide assistance in drafting advance directives).

23. See *infra* notes 179–182 and accompanying text; see also Dolgin, *supra* note 17, at 283–87.

24. See Dolgin, *supra* note 17, at 295–98.

25. INST. OF MED. OF THE NAT’L ACADS., *DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE* 117 (2015) [hereinafter INST. OF MED.].

26. See Michael J. Barry & Susan Edgman-Levitan, *Shared Decision Making—the Pinnacle of Patient-Centered Care*, 366 NEW ENG. J. MED. 780, 780 (2012).

27. Daniela J. Lamas, *When Faced with Death, People Often Change Their Minds*, N.Y. TIMES (Jan. 3, 2022), <https://www.nytimes.com/2022/01/03/opinion/advance-directives-death.html> (last visited Oct. 1, 2023) (quoting Dr. R. Sean Morrison, a palliative care physician).

28. See Megan S. Wright, *End of Life and Autonomy: The Case for Relational Nudges in End-of-Life Decision-Making Law and Policy*, 77 MD. L. REV. 1062, 1066 (2018).

29. JENNIFER NEDELSKY, *LAW’S RELATIONS: A RELATIONAL THEORY OF SELF, AUTONOMY, AND LAW* 3 (2011) [hereinafter NEDELSKY, *LAW’S RELATIONS*].

30. *Id.* at 4–5; Anita Ho, *Relational Autonomy or Undue Pressure? Family’s Role in Medical Decision-Making*, 22 SCANDINAVIAN J. CARING SCIS. 128, 131 (2008).

and misconstrued to only underlie empowerment if individual rights are viewed in isolation.³¹ Self-determination became synonymous with separateness and, therefore, connection to others was antithetical to empowerment.³² The theory of “relational autonomy” redefines this hierarchy and asserts that autonomy and identity development should include relationships and connections.³³ Those intimate and social relationships do not invalidate one’s agency but instead “enable our autonomy.”³⁴

Using a relational autonomy framework provides lawyers with an opportunity to align counseling with client preferences about end-of-life planning. This is achieved by recognizing that social connections and interdependence enhance client identity and decision-making.³⁵ Lawyers can frame discussions and counsel clients to consider the interests of others as well as include loved ones in the planning process. Many families already function using collaboration around shared values in decision-making. It is only natural that end-of-life decision-making would be conducted with the same closeness and connection.³⁶ Shifting client counseling away from traditional autonomy and a rights-based approach offers clients a new way to view end-of-life decision-making.

While lawyers have long prepared clients for death by formulating their estate planning wishes, some have been hesitant to prepare clients for their actual death. Attorneys advising clients on end-of-life matters have closely followed the autonomy script by emphasizing that death planning is an individualistic process. Too often, lawyers advising clients on end-of-life planning view their job as a narrow one: identify client objectives,

31. See NEDELSKY, *LAW’S RELATIONS*, *supra* note 29, at 248–49.

32. *Id.*

33. Yael Braudo-Bahat, *Towards a Relational Conceptualization of the Right to Personal Autonomy*, 25 AM. U. J. GENDER SOC. POL’Y & L. 111, 129 (2017) (using the concept of human “personhood,” which posits that each of us has both individual autonomy and is also a part of a web of relationships and connections). Said another way, “‘relational autonomy’ provides an alternative understanding of autonomy that acknowledges the many social and contextual constraints and pressures that may be placed on choices while simultaneously recognizing that there is value in self-determination.” Pamela Laufer-Ukeles, *Reproductive Choices and Informed Consent: Fetal Interests, Women’s Identity, and Relational Autonomy*, 37 AM. J.L. & MED. 567, 610 (2011); see also Catriona Mackenzie & Natalie Stoljar, *Introduction: Autonomy Refigured*, in *RELATIONAL AUTONOMY: FEMINIST PERSPECTIVES ON AUTONOMY, AGENCY, AND THE SOCIAL SELF* 3, 4 (Catriona Mackenzie & Natalie Stoljar eds., 2000) (arguing that none of the five major feminist critiques of autonomy—symbolic, metaphysical, care, postmodernist, or diversity—advocate for an absolute repudiation); NEDELSKY, *LAW’S RELATIONS*, *supra* note 29, at 3.

34. NEDELSKY, *LAW’S RELATIONS*, *supra* note 29, at 46.

35. See Braudo-Bahat, *supra* note 33, at 129–31.

36. Wright, *supra* note 28, at 1132–33.

follow applicable laws, and execute appropriate documents.³⁷ The flaw in the traditional autonomy model lies in its assumption that the client wants to only consider their own private interests and values. Lawyers can open the door to a more inclusive practice: one that starts with the view that as relational beings most of us choose to make difficult decisions by sharing information, values, and beliefs with others.

This Article recommends that lawyers use a relational autonomy lens to guide and counsel clients on end-of-life planning. Part I traces the evolution of traditional autonomy as the foundation of dying jurisprudence. Part II outlines how this restrictive rights-based approach fails clients. Part III examines what people want at the end of life. Part IV proposes a client counseling model that incorporates relational autonomy to enhance decision-making that accords with client choices and ensures their chosen death.

I. END-OF-LIFE JURISPRUDENCE IS GROUNDED IN TRADITIONAL AUTONOMY

The principle of respect for autonomous choice in end-of-life care and decision-making has deep roots.³⁸ Seeded in our constitutional right to be free from bodily intrusion, individual autonomy is heralded as the ideal.³⁹ Several high-profile cases formulated end-of-life jurisprudence, pitting the rights of incapacitated patients against the wishes of loved ones who argued for the right to discontinue treatment.⁴⁰ Courts grappled with how to uphold a patient's right to choose whether to utilize life-sustaining treatment when the patient had not documented those wishes and could no longer make decisions.⁴¹ The only considerations were the documented decisions of the individual or what the individual would have wanted if able to decide.⁴²

37. See Nachman, *supra* note 21, at 291.

38. Channick, *supra* note 12, at 586–87.

39. See Flick, *supra* note 14, at 1128–30.

40. See Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417 (Mass. 1977); *In re Quinlan*, 355 A.2d 647 (N.J. 1976); *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990); *In re Guardianship of Schiavo*, 780 So. 2d 176 (Fla. Dist. Ct. App. 2001), *aff'd*, *Schiavo ex rel. Schindler v. Schiavo*, 403 F.3d 1223 (11th Cir. 2005).

41. See Channick, *supra* note 12, at 581.

42. See *Saikewicz*, 370 N.E.2d at 430 (“[T]he goal is to determine with as much accuracy as possible the wants and needs of the individual involved.”).

This conceptualization of “traditional autonomy”⁴³ is defined as the right to self-governance or to live one’s life as one sees fit.⁴⁴ The insistence on considering only individual choice is now well-entrenched in the jurisprudence of dying. The right to govern oneself has long been upheld as a sacred, if not fundamental, right.⁴⁵ While self-determination should be a guiding force, strict adherence to this individualistic concept has meant the exclusion of a dying person’s loved ones. End-of-life decision-making and the evolution of the advance directive have remained firmly grounded in traditional autonomy theory. Advance directives have been the primary tool to allow people to maintain “exclusive control over end-of-life decisions.”⁴⁶ Patient autonomy is the essential “goal of [an] advance directive, as it acknowledges” that only the patient—not the physician or patient’s family—has “the ultimate right to direct medical treatment.”⁴⁷

A. *The Right to Bodily Autonomy and Self-Governance*

Bodily integrity and “the right of every individual to the possession and control of his own person, free from all restraint or interference,” are “more carefully guarded” and protected than other rights.⁴⁸ This deeply held attachment to autonomy as a liberty interest is the foundation for health law generally, as well as end-of-life decision-making.⁴⁹ This right underscores the importance of allowing patients to make their own decisions, even if those decisions are perceived as mistaken by others, because the patients are the ones most affected.⁵⁰

The centrality of autonomy in health law guides the governing medical doctrine of “informed consent.”⁵¹ This concept grew from the belief that “a non-emergency medical intervention performed without an

43. In this Article, I use “traditional autonomy” to describe what others have referred to as “personal autonomy.” See generally Braudo-Bahat, *supra* note 33. Others simply use “autonomy.” See generally Channick, *supra* note 12; Wright, *supra* note 28.

44. Channick, *supra* note 12, at 585.

45. Wright, *supra* note 28, at 1064–65 (citing *Union Pac. Ry. Co. v. Botsford*, 141 U.S. 250, 251 (1891)).

46. Bellard, *supra* note 15, at 803.

47. Gregory T. Holtz, *Understanding the Ethics of Empowerment: An Elder Law Lawyer’s Challenge or Obligation?*, 38 N. ILL. U. L. REV. 81, 103 (2017) (quoting Edward J. Larson & Thomas A. Eaton, *The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act*, 32 WAKE FOREST L. REV. 249, 249 (1997)).

48. *Botsford*, 141 U.S. at 251.

49. See Wright, *supra* note 28, at 1064–65; Shepherd, *supra* note 13, at 1697.

50. Flick, *supra* note 14, at 1129–30.

51. Channick, *supra* note 12, at 586–87.

individual's consent is an assault to which liability attaches."⁵² The modern conception is that, for a patient to knowingly consent to a procedure, the person must have all necessary information in order to make a well-reasoned medical decision.⁵³ A competent person's right is sufficiently broad to include the right to refuse treatment—even life-saving treatment.⁵⁴ Based on the autonomy framework, an individual with capacity has the nearly absolute right to refuse treatment.⁵⁵ The right to corporeal self-governance prevents any investigation into why the person may refuse life-sustaining treatment. There is no discussion as to the person's values, wishes, moral integrity, or religious beliefs. It is simply the right of the individual alone, based on privacy and self-determination.⁵⁶

B. *The Evolution of the End-of-Life Legal Landscape*

The legal landscape of end-of-life health care decision-making is relatively new and undeveloped, especially when compared to the well-established field of estate law. The New Jersey Supreme Court was the first to consider whether the right of privacy and individual autonomy, under its state constitution, allowed a father to terminate his incapacitated daughter's life-sustaining treatment.⁵⁷ In that case, *In re Quinlan*,⁵⁸ twenty-one-year-old Karen Quinlan was left in a persistent vegetative state after a medical condition when her father sought to discontinue life-sustaining treatment.⁵⁹ The court specifically found that the right of privacy was "broad enough to encompass a patient's decision to decline medical treatment."⁶⁰ Further, the court held that her "independent right of choice" overcomes the State's interest in preserving life.⁶¹ In addition to Ms. Quinlan's right to die, the court considered whether her father had

52. Alberto B. Lopez & Fredrick E. Vars, *Wrongful Living*, 104 IOWA L. REV. 1921, 1931 (2019). The doctrine of "informed consent" grew out of Justice Cardozo's decision in *Schloendorff v. Society of New York Hospital*, 105 N.E. 92 (N.Y. 1914), where Cardozo stated: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages." 105 N.E. 92, 93 (N.Y. 1914).

53. See Channick, *supra* note 12, at 586–87.

54. *Id.* at 587.

55. Shepherd, *supra* note 13, at 1697–98.

56. *Id.*

57. See Lopez & Vars, *supra* note 52, at 1933.

58. 355 A.2d 647 (N.J. 1976).

59. *Id.* at 651–57.

60. *Id.* at 663.

61. *Id.* at 664.

his own separate constitutional right as a parent.⁶² While the court grappled with “the rights of the incompetent, her family and society in general,”⁶³ it summarily foreclosed consideration of the interests of others.⁶⁴ The court made clear that the decision was based solely on Karen’s individual right and choice.⁶⁵ Intriguingly, the court noted that the only way for her privacy right to remain intact was to allow her family to decide if she would have chosen to terminate treatment.⁶⁶

In 1990, the United States Supreme Court addressed the issue for the first time in *Cruzan v. Director, Missouri Department of Health*,⁶⁷ where it considered whether the family of a young person in a persistent vegetative state could remove a feeding tube.⁶⁸ The Court held that an individual has a constitutional right to refuse life-sustaining treatment, but that a state could require clear and convincing evidence of the patient’s wishes.⁶⁹ Using an autonomy framework, the Court grappled with surrogate decision-making and, more specifically, whether to view a surrogate decision as the same right that a competent patient asserts as “an informed and voluntary choice.”⁷⁰ Instead of an individual determining for themselves whether to end life-sustaining treatment, “[s]uch a ‘right’ must be exercised for her.”⁷¹ The Court further noted that a state is entitled “to guard against potential abuses”—in particular, “unfortunate situations in which family members will not act to protect a patient.”⁷² Along with upholding individualistic notions of autonomy, the clear message of the Court was to view the inclusion of family members as risky and likely detrimental to patients.⁷³

A third case that captured the national attention, *In re Guardianship of Schiavo*,⁷⁴ involved another young person, Theresa Schiavo, who was in a persistent vegetative state.⁷⁵ The case applied the legal standard from

62. *Id.*

63. *Id.* at 652.

64. *Id.* at 664; Wright, *supra* note 28, at 1069.

65. *In re Quinlan*, 355 A.2d at 664.

66. *Id.*

67. 497 U.S. 261 (1990).

68. *Id.* at 278–79 (holding that the Fourteenth Amendment’s Due Process Clause protects the “liberty interest” in refusing unwanted medical treatment).

69. *Id.*; Shepherd, *supra* note 13, at 1703–04.

70. *Cruzan*, 497 U.S. at 280.

71. *Id.*

72. *Id.* at 281 (quoting *In re Jobes*, 529 A.2d 434, 447 (N.J. 1987)).

73. See Wright, *supra* note 28, at 1071.

74. 780 So. 2d 176 (Fla. Dist. Ct. App. 2001), *aff’d*, *Schiavo ex rel. Schindler v. Schiavo*, 403 F.3d 1223 (11th Cir. 2005).

75. *Id.* at 177.

Cruzan, requiring clear and convincing evidence for a surrogate to disconnect someone from life-sustaining treatment.⁷⁶ It solidified the indelible attachment to patient autonomy, defined only by what the patient would have done if able. *Schiavo* also presented a new issue: family members battling against each other to convince the court of the wishes of the incapacitated individual.⁷⁷ In a later case, the court described the legal right as “Theresa Schiavo’s right to make her own decision, independent of her parents and independent of her husband.”⁷⁸ Using an autonomy-centered framework, the court assumed her decision would not include the interests or input of her family.⁷⁹

C. Preserving Autonomy Through Advance Directives

In response to these heartbreaking cases and to preserve independent decision-making, the health care advance directive became the instrument to uphold the prized patient autonomy.⁸⁰ Beginning with the term “living will,” which first entered the legal lexicon in 1969, the last half century has seen the evolution and solidification of an individual’s right to decide in advance whether to terminate life-sustaining treatment.⁸¹ Luis Kutner, an international human rights lawyer, criticized the failure of the legal system to “recognize the right of the victim to die if he so desires.”⁸² Kutner is credited with coining the phrase “living will”⁸³ and connecting the right to terminate life-sustaining treatment to “an individual’s right of privacy.”⁸⁴

76. *Id.* at 179.

77. *Id.* at 178 (“Michael [Ms. Schiavo’s husband and guardian] and the Schindlers [Ms. Schiavo’s parents] simply cannot agree on what decision Theresa would make today if she were able to assess her own condition and make her own decision.”).

78. *In re Guardianship of Schiavo*, 851 So. 2d 182, 186 (Fla. Dist. Ct. App. 2003).

79. *See id.* at 186–87; *see also* Wright, *supra* note 28, at 1099.

80. *See* Sabatino, *Evolution*, *supra* note 18, at 212; *see also* Channick, *supra* note 12, at 625–26; Jane B. Baron, *Fixed Intentions: Wills, Living Wills, and End-of-Life Decision-Making*, 87 TENN. L. REV. 375, 404 (2020).

81. *See* Luis Kutner, *Due Process of Euthanasia: The Living Will, a Proposal*, 44 IND. L.J. 539, 543 (1969) (“[T]he current state of the law does not recognize the right of the victim to die if he so desires.”).

82. *Id.*

83. *Id.* at 551 (describing the document as “‘a living will,’ ‘a declaration determining the termination of life’” (emphasis omitted)).

84. *Id.* at 543.

At the same time *Quinlan* was being decided, California became the first state to pass legislation outlining a living will process in 1976.⁸⁵ The “living will” was conceived to protect an individual’s legal right to decide what kind and the extent of medical treatment they want, even when they can no longer express that choice.⁸⁶ Living wills were seen as the solution to balance concerns of being “hooked up to machines” too long or, conversely, being protected against premature “pulling of the plug.”⁸⁷

States moved quickly to pass statutes authorizing and creating the legal pathway for living wills.⁸⁸ By 1986, forty-one states had enacted statutes to facilitate this process.⁸⁹ It soon became clear that the narrow confines of the living will—only allowing for continuation or discontinuation of life-sustaining treatment—was not sufficient. The health care power of attorney offered the opportunity for patients to select a proxy, or substitute decision-maker.⁹⁰ Ultimately, many states began combining the living will and health care power of attorney into a single “advance directive” statute.⁹¹

“Advance directive” is the generalized term for the document that formally communicates one’s end-of-life wishes.⁹² This document dictates patient health care goals and specific instructions, and often identifies a surrogate decision-maker if the patient loses capacity.⁹³ To encourage states and provide uniformity, the National Conference of

85. The first statute of this nature, the California Natural Death Act, was originally adopted in 1976. See CAL. HEALTH & SAFETY CODE §§ 7185–7195 (West 1976) (repealed 1991); Lopez & Vars, *supra* note 52, at 1932. After its repeal, a new version was enacted, which is now codified at California Probate Code sections 4600 to 4806. Interestingly, shortly after the *Cruzan* ruling, the Society for the Right to Die received 300,000 requests for advance directive forms. Lewin, *supra* note 2.

86. See INST. OF MED., *supra* note 25, at 117.

87. *Id.*

88. See Channick, *supra* note 12, at 591; Baron, *supra* note 80, at 381–82.

89. Sabatino, *Evolution*, *supra* note 18, at 214.

90. *Id.*

91. *Id.* at 216.

92. *Id.* at 212. At least as late as 2019, the American Bar Association defined an “Advance Directive” as the

general term for any document in which you provide instructions about your health care wishes or appoint someone to make medical treatment decisions for you when you are no longer able to make them for yourself. Living wills and Durable Powers of Attorney for health care are both types of health care advance directives.

Terry Eggenberger, George R. Luck, Heather Howard & Dana E. Prescott, *Advance Directives and Family Practice: Implications and Ethics for “Greying” Family Systems and Interdisciplinary Collaboration*, 32 J. AM. ACAD. MATRIM. LAWS. 1, 9 (2019); see also *Living Wills, Health Care Proxies, & Advance Health Care Directives*, AM. BAR ASS’N [hereinafter *Living Wills*], https://www.americanbar.org/groups/real_property_trust_estate/resources/estate_planning/living_wills_health_care_proxies_advance_health_care_directives/ (last visited Nov. 3, 2023).

93. Sabatino, *Evolution*, *supra* note 18, at 212.

Commissioners on Uniform State Laws promulgated the Uniform Health Care Decision Act in 1993, a template that states could utilize.⁹⁴ Subsequently, states began drafting legislation to define applicable procedures, and now every state recognizes some form of advance directive.⁹⁵ While state laws protect medical self-determination, the patient must formalize those decisions in an advance directive. As part of the Patient Self-Determination Act of 1990, health care providers that accept Medicare and Medicaid are required to advise all patients of their rights to record their end-of-life wishes.⁹⁶ Facilities are required to provide patients with written directives and document them in a patient's chart.⁹⁷

The process of executing advance directives reinforces the belief that an individual should make end-of-life decisions alone without consulting family and friends. A likely scenario may look like this: a client meets alone with a lawyer to discuss whether they would want to be kept alive if they were in a persistent vegetative state. The lawyer may say, "This is your chance to be in the driver's seat. You, and you alone, can decide how you want your life to end." This type of legal counseling assumes that the client's sole motivation when facing death is to preserve autonomy.⁹⁸ This preoccupation with traditional autonomy "focuses solely on avoiding the prolongation of dying and achieving a sense of control."⁹⁹ Advance directives reinforce this notion by focusing clients on narrow, static issues like which specific treatment to choose or withhold, rather than on the larger conversation about dying.¹⁰⁰

II. END-OF-LIFE COUNSELING USING A TRADITIONAL AUTONOMY MODEL FAILS CLIENTS

Most lawyers no longer approach end-of-life planning with clients in a purely transactional manner. Those who undertake practice as "elder law attorneys" especially understand that today's older clients expect more than completion of estate planning forms.¹⁰¹ Lawyers assisting older

94. See UNIF. HEALTH-CARE DECISIONS ACT § 4 (NAT'L CONF. OF COMM'RS ON UNIF. STATE L. 1994). Ultimately, only seven states have adopted this statute. See Baron, *supra* note 80, at 382 n.28.

95. See Ed de St. Aubin, Sheila Baer & Joan Ravanelli Miller, *Elders and End-of-Life Medical Decisions: Legal Context, Psychological Issues, and Recommendations to Attorneys Serving Seniors*, 7 MARQ. ELDER'S ADVISOR 259, 264–65 (2006).

96. Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, §§ 4206, 4751, 104 Stat. 1388, 1388-115–117, 1388-204–206 (1990).

97. Lopez & Vars, *supra* note 52, at 1935.

98. Bellard, *supra* note 15, at 810.

99. *Id.*

100. *Id.* at 811.

101. Holtz, *supra* note 47, at 86–87.

clients are often drawn to the holistic practice and the goal of “preserving and protecting the dignity, sanctity, and worth of the elder client’s life.”¹⁰² Even with this mindset, lawyers preparing clients for the end of life are still steeped in ensuring the client maintains control, influence, and sole decision-making authority.

Because autonomy underpins the law of end-of-life decision-making, the default belief is that “decisions about death are the legitimate prerogative of no one but the dying person.”¹⁰³ This traditional conception of autonomy creates a “negative liberty interest establishing a zone of privacy and noninterference around each person.”¹⁰⁴ As a consequence, this isolated decision-making model excludes consideration of the values or voices of others.¹⁰⁵ The elevation of patient interests separate and apart has meant that any involvement by family or friends is seen to “muddle the patient’s decision-making process.”¹⁰⁶ Instead of bolstering autonomy, a patient decision that involves the interests of others can be viewed as “tainted.”¹⁰⁷ If a patient defers to others, they are seen as a poor decision-maker or, presumptively, the victim of undue influence.¹⁰⁸

The rigid adherence to autonomy principles in the end-of-life context has created an unworkable framework.¹⁰⁹ Advance directives were heralded as the solution to preserving autonomy and preventing end-of-life tragedies. When lawyers rely on this model and over-emphasize client self-determination, however, it hinders a more substantive conversation. The result is clients do not delve into their thoughts, values, and beliefs about death and may refrain from meaningful decision-making.

A. Advance Directives Are Underutilized and Ineffective

While advance directives were hailed as the solution to prevent further end-of-life tragedies like Nancy Cruzan’s, they remain woefully underutilized.¹¹⁰ Their primary purpose was to create a physical, portable document with clear instructions for providers and loved ones to ensure

102. *Id.* at 86.

103. Burt, *supra* note 11, at 11.

104. Channick, *supra* note 12, at 585–86.

105. Wright, *supra* note 28, at 1066; Shepherd, *supra* note 13, at 1697.

106. Ho, *supra* note 30, at 130.

107. *Id.*

108. *Id.*

109. See Channick, *supra* note 12, at 621.

110. See Dolgin, *supra* note 17, at 247.

compliance with patient wishes.¹¹¹ They were designed so that even once the person became incapacitated, the document would safeguard earlier choices.¹¹² Unfortunately, only about one-third of Americans have completed an advance directive, and completion rates are even lower for low-income communities.¹¹³

The reasons offered for low completion rates include challenges with the written form itself, as well as use and interpretation of written directives.¹¹⁴ Like all estate planning documents, advance directives contain legalese and formal requirements that can discourage some potential clients.¹¹⁵ As one author quipped, “[t]he world abounds in dreadfully drafted forms because writing complex instructions for the future is crushingly difficult.”¹¹⁶ In addition to confusing legal language, directives include complicated medical terms, such as “terminal condition” or “persistent vegetative state,”¹¹⁷ that many people might not fully understand.¹¹⁸ Further, most state statutes mandate signature and notarization, which may create a barrier.¹¹⁹ As with all legal assistance, lack of access to a lawyer to complete forms due to finances or English proficiency creates challenges as well.¹²⁰

Like any legal document, directives face limitations due to both their restrictive nature when written too narrowly and the risk of being ignored

111. Grace W. Orsatti, *Attorneys as Healthcare Advocates: The Argument for Attorney-Prepared Advance Healthcare Directives*, 50 J.L. MED. & ETHICS 157, 161 (2022).

112. *Id.*

113. See Kuldeep N. Yadav, Nicole B. Gabler, Elizabeth Cooney, Saida Kent, Jennifer Kim, Nicole Herbst, Adjoa Mante, Scott D. Halpern & Katherine R. Courtright, *Approximately One in Three US Adults Completes Any Type of Advance Directive for End-of-Life Care*, 36 HEALTH AFFS. 1244, 1244 (2017); Laura C. Hanson & Eric Rodgman, *The Use of Living Wills at the End of Life: A National Study*, 156 ARCHIVES INTERNAL MED. 1018, 1018 (1996) (finding that patients who are Black, underinsured, cognitively impaired, or have little education are the least likely to execute an advance directive). In 2007, researchers estimated that as few as four percent and as many as twenty-five percent of people had executed advance directive documents. Henry S. Perkins, *Controlling Death: The False Promise of Advance Directives*, 147 ANNALS INTERNAL MED. 51, 52 (2007).

114. See Gallanis, *supra* note 21, at 1027.

115. See Orsatti, *supra* note 111, at 161 (“[A]ttorney-prepared documents are criticized for overly complicated language that may be difficult to interpret by the clinician, client, and agent.”).

116. Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, HASTINGS CTR. REP., Mar.–Apr. 2004, at 30, 34.

117. Brooke M. Benzio, *Advance Health Care Directives: Problems and Solutions for the Elder Law and Estate Planning Practitioner*, 26 ST. THOMAS L. REV. 37, 40 (2013).

118. See *id.* at 40–41 (describing situations where the advance directive form does not cover the patient’s medical needs or reality, such as when a provider may be unable to follow a directive’s requirements where a patient is not technically in an “irreversible coma” and the document requires that status).

119. Baron, *supra* note 80, at 392.

120. *Id.*

or ineffective when they are overly vague.¹²¹ To account for the myriad of medical possibilities a person may face, many directives are drafted to be overly broad to allow later flexibility. The unfortunate result is that the lack of specificity leads to poor compliance.¹²² Likely the biggest obstacle to the use of advance directives is the inherent inability to account for the various illnesses and treatment decisions that arise.¹²³ Of those patients who do execute directives, many fail to communicate their existence to medical providers.¹²⁴ Often, these documents are tucked away in a remote file cabinet and never discovered by family members. Assuming the document is located and shared with medical providers, questions arise as to whether this is the individual's true wishes or if they changed their mind over time.¹²⁵ Once a provider is aware of the directive, several factors hamper compliance, including conflict with hospital policy and questions about patient capacity at execution.¹²⁶ Several studies revealed actual resistance by physicians to abide by patient wishes at the end of life.¹²⁷

121. Linda C. Fentiman, *Privacy and Personhood Revisited: A New Framework for Substitute Decisionmaking for the Incompetent, Incurably Ill Adult*, 57 GEO. WASH. L. REV. 801, 824–25 (1989).

122. Lopez & Vars, *supra* note 52, at 1938–39.

123. Fentiman, *supra* note 121, at 824 (“This is so both because what seems like a grave imposition on the quality of life to a thirty year old might appear to be an entirely reasonable restriction at the age of seventy, and also because it is difficult to foresee precisely the type of incompetency and incurable illness that might occur.”).

124. Melinda A. Lee, Kenneth Brummel-Smith, Jan Meyer, Nicholas Drew & Marla R. London, *Physician Orders for Life-Sustaining Treatment (POLST): Outcomes in a PACE Program*, 48 J. AM. GERIATRICS SOC’Y 1219, 1224 (2000); Orsatti, *supra* note 111, at 162 (“[S]uch paperwork does not find its way to the client’s physician or healthcare agent, and rather than being made part of a client’s medical record, the document is instead filed and forgotten once the client leaves the law office.”).

125. See Gallanis, *supra* note 21, at 1028. This became a more likely possibility when the Uniform Health-Care Decisions Act was passed, specifically delineating that a directive could be revoked or modified by a subsequent writing. *Id.* Some states have created state registries for health care directives where individuals can pay a fee and their directive will be web accessible. *E.g.*, N.D. CENT. CODE § 23-06.5-19 (2019).

126. Nachman, *supra* note 21, at 300; see also Sarah Hooper, Charles P. Sabatino & Rebecca L. Sudore, *Improving Medical-Legal Advance Care Planning*, 60 J. PAIN & SYMPTOM MGMT. 487, 492 (2020) (“[L]egal advance directives are often incomprehensible, are too lengthy, or contain specific treatment wishes which are not pertinent to the clinical situation at hand.”); Lee et al., *supra* note 124, at 1219 (noting that some physicians believe an advance directive must be converted into a medical order); David A. Asch, John Hansen-Flaschen & Paul N. Lanken, *Decisions to Limit or Continue Life-Sustaining Treatment by Critical Care Physicians in the United States: Conflicts Between Physicians’ Practices and Patients’ Wishes*, 151 AM. J. RESPIRATORY & CRITICAL CARE MED. 288, 290 tbl.3 (1995) (finding that while ninety-six percent of physician respondents reported having withdrawn life-sustaining treatment, thirty-four percent reported they had declined to do so at least once when asked by a patient or surrogate).

127. See Nachman, *supra* note 21, at 303; Lee et al., *supra* note 124, at 1219; Asch et al., *supra* note 126, at 291 tbl.5 (demonstrating that many physicians reported having withheld life-sustaining treatment without patient or surrogate consent and that some did so over the objection of patient or family member); Joan M. Teno, Marguerite Stevens, Stephanie Spernak & Joanne Lynn, *Role of*

In response to low completion rates, success was simple: increase client understanding of the directives and ensure the medical community's knowledge and compliance with the concomitant requirements.¹²⁸ Educators, policymakers, and medical and legal professionals rolled out innovative and thoughtful ideas to increase use.¹²⁹ Moreover, although the number of people with advance directives has increased substantially, execution does not equal success.¹³⁰ Despite the longstanding belief that advance directives will ensure patient self-governance, many studies reveal that they fail in the intended goal "to promote compliance with a patient's preference[]" at end of life.¹³¹

B. Clients Avoid Conversations About Death

It is estimated that one-quarter of all adults, including those aged seventy-five and older, have not thought about, discussed, or written down their end-of-life wishes.¹³² While many older adults may expect to be in control of dying decisions, a variety of factors can counteract that desire. For some, the end of life presents physical or cognitive challenges that prevent them from making their own care or treatment decisions. For others, they may be unable or unwilling to recognize when the end of life is approaching and consequently limited in their ability to make end-of-life choices.¹³³ Lastly, the anxiety-producing nature of discussing illness and death creates reluctance and denial in many people.¹³⁴ Death anxiety varies by individual but includes fear of what will happen after death or

Written Advance Directives in Decision Making: Insights from Qualitative and Quantitative Data, 13 J. GEN. INTERNAL MED. 439, 441 (1998) (finding patient or surrogate wishes are only one factor considered by physicians, although researchers did not find evidence of a physician ignoring an advance directive).

128. See Nachman, *supra* note 21, at 299.

129. For example, the non-profit Aging with Dignity created Five Wishes, a multi-part document that supplements picking an agent and selecting medical treatment with details on comfort care and specific preferences. See FIVE WISHES, AGING WITH DIGNITY, <https://www.fivewishes.org/five-wishes-sample.pdf> [<https://perma.cc/TH6J-X5KW>]; see also Nachman, *supra* note 21, at 328–31 (discussing innovative programs and alternate forms).

130. See Lopez & Vars, *supra* note 52, at 1935 (demonstrating how the number of people who completed an advance directive increased from forty-seven percent in 2000 to seventy-two percent in 2010).

131. *Id.* at 1924.

132. See INST. OF MED., *supra* note 25, at 3; see also Dolgin, *supra* note 17, at 247.

133. INST. OF MED., *supra* note 25, at 11.

134. Bruce J. Winick, *Client Denial and Resistance in the Advance Directive Context: Reflections on How Attorneys Can Identify and Deal with a Psycholegal Soft Spot*, 4 PSYCH. PUB. POL'Y & L. 901, 903 (1998); see Kathleen M. Boozang, *An Intimate Passing: Restoring the Role of Family and Religion in Dying*, 58 U. PITT. L. REV. 549, 554 (1997) ("Medicine and contemporary culture have combined to erase death from our imaginations."); see also Burt, *supra* note 11, at 10.

whether one will be in pain while dying.¹³⁵ In a culture obsessed with anti-aging and youth, the consequence for many is to ignore death, avoid discussing it, and attempt to escape it.¹³⁶ Instead of contemplating death or thinking deeply about the end of one's life, many of us choose to ignore the inescapable.¹³⁷

An additional obstacle to completing advance directives is that they are “inherently speculative in nature.”¹³⁸ It is counterintuitive for a healthy person to contemplate a hypothetical event or disease, or the end of life, which seems far off in the future. Without a specific diagnosis or details of possible treatment options, individuals must decide now what their wishes and desires will be later. When completing advance directives and choosing whether to have life sustaining treatment, clients are asked questions about narrow hypothetical situations—“If you are in a permanent vegetative state, do you want to have nutrition, hydration, or a ventilator?”¹³⁹ There is an inherent disconnect between when advance directives are created—when the person is in a “cool” or detached state—and when the predicted event will occur—when the person is in a “hot” or emotional place.¹⁴⁰ Patients may be less inclined to make end-of-life decisions in an unrealistic, theoretical situation devoid of the detailed information that most patients in a real situation possess.¹⁴¹

135. Mark Glover, *A Therapeutic Jurisprudential Framework of Estate Planning*, 35 SEATTLE U. L. REV. 427, 434–35 (2012). Psychologists have identified seven concerns people have related to death:

(1) they can no longer have any life experiences; (2) they may be uncertain about what will happen to them if there is a life after death; (3) they may be afraid of what will happen to their bodies after death; (4) they realize they will no longer be able to care for their dependents; (5) they realize their death may cause grief to their relatives and friends; (6) they realize that all their plans and projects will come to an end; and (7) they may be afraid that the process of dying will be painful.

Id. at 435.

136. Boozang, *supra* note 134, at 554; Dolgin, *supra* note 17, at 247.

137. See SALLIE TISDALE, *ADVICE FOR FUTURE CORPSES (AND THOSE WHO LOVE THEM)* 32 (2018); see also Winick, *supra* note 134, at 903 (providing a thorough overview of the psychological underpinnings of denial as a defense mechanism).

138. Orsatti, *supra* note 111, at 157.

139. Baron, *supra* note 80, at 406.

140. *Id.* at 400 (discussing George Loewenstein, *Hot–Cold Empathy Gaps and Medical Decision Making*, 24 HEALTH PSYCH. S49 (Supp. 2005)); see also *id.* at 402 (arguing that reliance on older directives, created in the “cool” state of mind, may be more reasonable than decisions made during the moment that may be impacted by “stress, emotion, and the potential for bias and suboptimal decision making” (quoting Peter H. Ditto, Nikki A. Hawkins & David A. Pizarro, *Imagining the End of Life: On the Psychology of Advance Medical Decision Making*, 29 MOTIVATION & EMOTION 481, 497 (2005))). Another scholar, bioethicist Rebecca Dresser, argues that once a patient becomes “incompetent” at the end of life, we can no longer attach earlier goals and wishes from their directive to their current “incompetent” state of being. Rebecca Dresser, *Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law*, 28 ARIZ. L. REV. 373, 393 (1986).

141. Baron, *supra* note 80, at 399–400.

Research indicates that when it comes to end-of-life decision-making, many people simply change their minds.¹⁴² Additionally, illness and hospitalization alter patient preferences about life-sustaining treatment.¹⁴³ Some argue that a person receiving treatment, years after executing an advance directive, is a fundamentally different person from the one who chose the earlier options.¹⁴⁴ That is to say that “perhaps former selves should not be able to bind later selves in the way living wills contemplate.”¹⁴⁵ There is evidence demonstrating that this is particularly true for people later in life when deciding whether to prolong their life with medical intervention.¹⁴⁶ Even if someone does not change their mind about the basics of an advance directive, it is difficult to extrapolate from those narrowly identified requests to specific medical treatment for various illnesses. A patient loses the ability to change their mind when circumstances change, as “[t]he law wants to freeze time in certainty of decision.”¹⁴⁷

C. Surrogates Are Ill-Prepared to Decide

Evidence suggests that approximately forty percent of adults in hospitals are incapable of making their own treatment decisions due to unconsciousness, cognitive impairment, or inability to communicate a choice.¹⁴⁸ That number is as high as seventy percent for those over sixty years of age and at the end of life.¹⁴⁹ That means that despite the emphasis placed on patient autonomy, an extraordinary number of end-of-life treatment decisions are made by surrogates, not patients.¹⁵⁰ Surrogate decision-making jurisprudence is grounded in the same series of cases beginning with *Quinlan* in the 1970s. This jurisprudence retains the focus on patient autonomy and the right to self-determination.¹⁵¹ Competent

142. Lopez & Vars, *supra* note 52, at 1939; Fagerlin & Schneider, *supra* note 116, at 34.

143. See Fagerlin & Schneider, *supra* note 116, at 34.

144. Lopez & Vars, *supra* note 52, at 1937 (citing Rebecca Dresser, *Precommitment: A Misguided Strategy for Securing Death with Dignity*, 81 TEX. L. REV. 1823, 1823 (2003) [hereinafter Dresser, *Precommitment*]).

145. Fagerlin & Schneider, *supra* note 116, at 30.

146. Dresser, *Precommitment*, *supra* note 144, at 1835.

147. Flick, *supra* note 14, at 1146.

148. See INST. OF MED., *supra* note 25, at 119.

149. *Id.*

150. Michael H. Limerick, *The Process Used by Surrogate Decision Makers to Withhold and Withdraw Life-Sustaining Measures in an Intensive Care Environment*, 34 ONCOLOGY NURSING F. 331, 331 (2007) (citing Valerie Swigart, Charles Lidz, Victoria Butterworth & Robert Arnold, *Letting Go: Family Willingness to Forgo Life Support*, 25 HEART & LUNG 483, 484 (1996)).

151. Wright, *supra* note 28, at 1071–72.

adults have the right to designate another individual, a surrogate or proxy, to make health care decisions on their behalf if they become unable to do so.¹⁵² The principal goal of appointing a proxy is to ensure that the treatment goals of the patient are upheld.¹⁵³

In choosing a surrogate, most states have created a hierarchal, default standard with a single individual authorized to be placed in the shoes of the patient.¹⁵⁴ For example, in Washington State the surrogate order of priority starts with an appointed guardian, then moves to an agent authorized under a power of attorney, before considering a family member.¹⁵⁵ This suggests that a guardian or agent would be more likely to follow the path the patient would have chosen. This hierarchical framework fails to account for the reality that “families often consist of a constellation of members” who participate in decision-making.¹⁵⁶ It further reinforces the isolating model of a single person making decisions without additional input from others who know the patient.

Reliance on traditional autonomy also plays a role in how surrogates are tasked with making decisions for incapacitated patients.¹⁵⁷ Many states have codified a two-step process to intentionally guide surrogates or health care agents using the autonomy model.¹⁵⁸ This requires the surrogate to first follow the “substituted judgment” standard and choose a treatment option as if they are the patient.¹⁵⁹ Courts have supported this approach for its “straightforward respect for the integrity and autonomy

152. The use of the word “proxy” will be used interchangeably with “surrogate” and/or “agent.” A health care agent is a person designated in an advance directive, while a health care proxy is any designated substitute decision-maker and can include either a guardian or conservator. A surrogate refers to the person who, by default, becomes the decision-maker when no one is appointed. *See* INST. OF MED., *supra* note 25, at 118 n.1.

153. *See* Nina A. Kohn, *Improving Healthcare Decisions Through a Shared Preferences and Values Approach to Surrogate Selection*, in *NUDGING HEALTH: HEALTH LAW AND BEHAVIORAL ECONOMICS* 297, 298 (I. Glenn Cohen, Holly Fernandez Lynch & Christopher T. Robertson eds., 2016).

154. Thomas L. Hafemeister, *End-of-Life Decision Making, Therapeutic Jurisprudence, and Preventive Law: Hierarchical v. Consensus-Based Decision-Making Model*, 41 *ARIZ. L. REV.* 329, 340–41 (1999).

155. WASH. REV. CODE § 7.70.065(1)(a) (2022).

156. Hafemeister, *supra* note 154, at 350.

157. *See* Shepherd, *supra* note 13, at 1699–700.

158. The Uniform Health-Care Decisions Act provides model legislation with this same decision-making process, directing an agent to follow the known directions, then substituted judgment, followed by the patient’s best interests. UNIF. HEALTH-CARE DECISIONS ACT §§ 2(e), 5(f) (NAT’L CONF. OF COMM’RS ON UNIF. STATE L. 1994); *see also* Wright, *supra* note 28, at 1073–74; Sabatino, *Evolution*, *supra* note 18, at 219.

159. Shepherd, *supra* note 13, at 1702; Wright, *supra* note 28, at 1073–74. For example, in Washington State this requires a surrogate to first determine, in good faith, if the wishes of the incapacitated patient are known. *See* WASH. REV. CODE § 7.70.065(1)(c) (2022).

of the individual.”¹⁶⁰ If there is no evidence of what the patient would have chosen, only then can the surrogate follow a “best interest” standard.¹⁶¹ This hierarchy tracks with the commitment to preserve patient autonomy, prioritizing it over decisions made in collaboration with others.¹⁶² Consideration of the interests of another is viewed as subjugating the patient’s interests.¹⁶³

An objective of advance directives was to prevent agonizing decisions by substitute decision-makers.¹⁶⁴ The decision-making burden placed on surrogates can be substantial. Unfortunately, studies reveal that surrogates can be unavailable, unreliable, or overwhelmed.¹⁶⁵ Surrogate decision-making can be a very stressful and emotional process for family members as they consider competing interests and factors. This is particularly true if family members are trying to determine what the dying person would choose when they do not have adequate information.¹⁶⁶

Ethicists suggest the challenge is that surrogates are forced to make end-of-life decisions for others “in the midst of anticipatory grief.”¹⁶⁷ Health care studies examining the accuracy of surrogate decision-making find that surrogate decisions are congruent with patient treatment preferences sixty-eight percent of the time.¹⁶⁸ One study found little

160. Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 431 (Mass. 1977).

161. Sabatino, *Evolution*, *supra* note 18, at 219. Again, for example, see WASH. REV. CODE § 7.70.065(1)(c) (2022).

162. See Wright, *supra* note 28, at 1073–74.

163. Shepherd, *supra* note 13, at 1699 (“The law does not generally promote respect for autonomy as including respect for choices that benefit others’ interests over the patient’s interests . . .”).

164. See Karen L. Schultz & Timothy D. Schultz, *Advance Directives: A Primer*, 63 TEX. BAR J. 1034, 1036 (2000) (noting that advance directives may diminish “the anxiety and confusion surrounding choices to be made by family and friends”); INST. OF MED., *supra* note 25, at 137.

165. Fagerlin & Schneider, *supra* note 116, at 36–37.

166. Wright, *supra* note 28, at 1083 n.119.

167. Michael Cholbi, *Grief and End-of-Life Surrogate Decision-Making*, in ETHICS AT THE END OF LIFE: NEW ISSUES AND ARGUMENTS 201, 209 (John K. Davis ed., 2017).

168. See David I. Shalowitz, Elizabeth Garrett-Mayer & David Wendler, *The Accuracy of Surrogate Decision Makers: A Systematic Review*, 166 ARCHIVES INTERNAL MED. 493, 493 (2006); Jessica Bryant, Lesli E. Skolarus, Barbara Smith, Eric E. Adelman & William J. Meurer, *The Accuracy of Surrogate Decision Makers: Informed Consent in Hypothetical Acute Stroke Scenarios*, BIOMED CENT. EMERGENCY MED. (Nov. 13, 2013), <https://bmccemergmed.biomedcentral.com/articles/10.1186/1471-227X-13-18> (last visited Nov. 18, 2023). *But see* Patricia Bomba, *Landmark Legislation in New York Affirms Benefits of a Two-Step Approach to Advance Care Planning Including MOLST: A Model of Shared, Informed Medical Decision-Making and Honoring Patient Preferences for Care at the End of Life*, 17 WIDENER L. REV. 475, 481–82 (2011) (citing Kristen M. Coppola, Peter H. Ditto, Joseph H. Danks & William D. Smucker, *Accuracy of Primary Care and Hospital-Based Physicians’ Predictions of Elderly Outpatients’ Treatment Preferences with and Without Advance Directives*, 161 ARCHIVES INTERNAL MED. 431, 436 tbl.2 (2001)) (finding that family members correctly identified patient’s wishes more than seventy percent of the time).

difference in surrogate ability to correctly determine patient wants with or without an advance directive in place.¹⁶⁹ Reasons for incongruence between surrogate and patient choices can include a simple lack of knowledge of the patient's wishes as well as surrogate overconfidence in what the patient would decide.¹⁷⁰ Additionally, surrogates tend to substitute their own preferences for that of the patient.¹⁷¹ Completing an advance directive alone does not prevent this misalignment between patient preferences and surrogate actions.

D. Advance Directives Fail in the Promise of Control

Despite these challenges and the purported failure of advance directives, advance directives are still proposed as the primary instruments offered for people to maintain “exclusive control over end-of-life decisions.”¹⁷² The essential goal of an advance directive is to dictate that only the patient—not the physician or patient's family—has the ultimate right to direct medical treatment.¹⁷³ In essence, advance directives exist as negative rights—the right to refuse treatment—which limit the full picture of end-of-life planning.¹⁷⁴

Contrary to their professed objective, advance directives promise only the illusion of autonomy, choice, and control.¹⁷⁵ Much of the legal landscape of advance directives stemmed from situations where a family was left agonizing and wondering what the (now incapacitated) patient would have wanted.¹⁷⁶ Education and preparation of the future patient to

169. Peter H. Ditto, Joseph H. Danks, William D. Smucker, Jamila Bookwala, Kristen M. Coppola, Rebecca Dresser, Angela Fagerlin, R. Mitchell Gready, Renate M. Houts, Lisa K. Lockhart & Stephen Zydzanski, *Advance Directives as Acts of Communication: A Randomized Controlled Trial*, 161 ARCHIVES INTERNAL MED. 421, 423 (2001). In the study, 401 outpatients sixty-five years or older and their chosen surrogate decision-makers were asked to predict patients' preferences for four life-sustaining medical treatments in nine illness scenarios without the benefit of a patient-completed advance directive. *See id.* at 421. Results were compared with surrogates who made predictions after reviewing either a scenario-based or a value-based directive completed by the patient. *Id.* at 423. The results showed that no intervention produced significant improvements in the surrogate's accuracy in any illness scenario or for any medical treatment. *See id.* at 424–25.

170. Kohn, *supra* note 153, at 299.

171. *Id.*

172. Bellard, *supra* note 15, at 803.

173. Holtz, *supra* note 47, at 103; Gary S. Winzelberg, Laura C. Hanson & James A. Tulsky, *Beyond Autonomy: Diversifying End-of-Life Decision-Making Approaches to Serve Patients and Families*, 53 J. AM. GERIATRICS SOC'Y 1046, 1046 (2005) (“The fundamental constraint on advance directives is that they derive their ethical and legal justifications from the principle of individual autonomy.”).

174. Winzelberg et al., *supra* note 173, at 1046.

175. Perkins, *supra* note 113, at 54; *see also* Burt, *supra* note 11, at 9.

176. *See* Channick, *supra* note 12, at 586–87.

make an autonomous decision ahead of time were viewed as the preventive roadmap.¹⁷⁷

Lawyers advising clients believed that completing advance directives would ensure a client's end-of-life wishes were known and respected. They intended to preserve the client's ability to control the end of their life.¹⁷⁸ The medical community also motivated to improve end-of-life care for patients implemented a model called "Advance Care Planning" (ACP).¹⁷⁹ ACP is broadly defined as "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care."¹⁸⁰ More specifically, the patient, in consultation with family or surrogates and medical providers, plans for future health care if they become incapable of making those decisions.¹⁸¹ ACP is intended to be an evolving, ongoing process where the patient is informed of medical options and empowered to plan and choose future treatment.¹⁸²

The medical community sold ACP as the solution to counter poor end-of-life care.¹⁸³ This assumption led to widespread public initiatives promoting its use, physician reimbursement for advance care planning discussions, and use as a quality measure.¹⁸⁴ While ACP increased the

177. See Fagerlin & Schneider, *supra* note 116, at 31.

178. See Bellard, *supra* note 15, at 804.

179. Sabatino, *Evolution*, *supra* note 18, at 224–25.

180. Rebecca L. Sudore, Hillary D. Lum, John J. You, Laura C. Hanson, Diane E. Meier, Steven Z. Pantilat, Daniel D. Matlock, Judith A.C. Rietjens, Ida J. Korfage, Christine S. Ritchie, Jean S. Kutner, Joan M. Teno, Judy Thomas, Ryan D. McMahan & Daren K. Heyland, *Defining Advance Care Planning for Adults: A Consensus Definition from a Multidisciplinary Delphi Panel*, 53 J. PAIN & SYMPTOM MGMT. 821, 821 (2017). The American Bar Association defines "Advance Care Planning" as

[a] process for setting goals and plans with respect to medical care and treatments. It requires conversations between the individual and his or her family, key health care providers, and anyone else who may be involved in decision-making. It can begin at any point in a person's life, regardless of his or her current health state and, ideally, is documented in an advanced directive or recorded in your medical record, revisited periodically, and becomes more specific as your health status changes.

Charles P. Sabatino, *Top Ten Myths and Facts About Health Care Advance Directives*, 37 BIFOCAL 6, 6 (2015).

181. See Peter A. Singer, Gerald Robertson & David J. Roy, *Bioethics for Clinicians: 6. Advance Care Planning*, 155 CAN. MED. ASS'N J. 1689, 1689 (1996).

182. Katherine Hayes, Michal McDowell & Sydney Reuben, *Providing Patient-Centered Care: An Examination of the Policy and Political Barriers and Proposed Options to Improve Care for Persons with Advanced Illness*, 10 NAELA J. 1, 3 (2014).

183. See R. Sean Morrison, Diane E. Meier & Robert M. Arnold, *What's Wrong with Advance Care Planning?*, 326 J. AM. MED. ASS'N 1575, 1575 (2021).

184. *Id.* Five Wishes is a form created by Aging with Dignity designed to be a simple, non-legalistic tool that could be used in a variety of states. Sabatino, *Evolution*, *supra* note 18, at 226. It is now widely used and meets the advance directive legal requirements of most states. See *id.* POLST, which

number of doctors engaging in dialogue, “a doctor’s willingness to discuss death is not synonymous with a comprehensive plan for [end-of-life] care.”¹⁸⁵ Despite patient desire for better communication with their physicians, providers are not trained in interpersonal communication.¹⁸⁶ In addition, many providers feel uncomfortable or do not have time for in-depth discussions.¹⁸⁷ Further, medical providers rarely address non-medical issues, such as self-determination or family dynamics, all of which are integral to end-of-life discussions.¹⁸⁸

Unfortunately, a 2021 examination of eighty systematic reviews “found no evidence that ACP was associated with influencing medical decision making at the end of life, enhancing the likelihood of goal-concordant care, or improving patients’ or families’ perceptions of the quality of care received.”¹⁸⁹ Many medical providers have wondered what to do if the current model of ACP does not achieve the intended goal of better end-of-life care.¹⁹⁰ Some of the reasons are similar to the inadequacy of advance directives: the gap between hypothetical situations and real-world decisions, patient preferences changing over time, and the fact that the end of life is emotionally fraught and complicated.¹⁹¹ Simply put, “[t]reatment choices near the end of life are not simple, consistent, logical, linear, or predictable but are complex, uncertain, emotionally laden, and fluid.”¹⁹²

There have been many reasons proffered for the failure of advance directives and ACP. Some argue that advance directives fail because the two distinct goals of end-of-life planning are in conflict: protecting an individual’s right to determine the boundaries of their care and protecting health care professionals from potential liability.¹⁹³ Both the medical and

is not an advance directive, was first created in Oregon in the 1990s but has been used in many states since then. *See id.* at 228–29. It is a medical form that provides the patient’s current medical care goals, and in particular whether the person wants to be resuscitated or not. *See id.* at 229–30.

185. Sarah E. Ryan, *Increasing Legal Support for End-of-Life Planning in the United States: How Probate and Family Attorneys Can Contribute to a Culture of Dignified Dying*, 30 QUINNIPIAC PROB. L.J. 335, 336 (2017).

186. Orsatti, *supra* note 111, at 162–63.

187. Wright, *supra* note 28, at 1087.

188. *Id.* at 1087–88.

189. Morrison et al., *supra* note 183, at 1575.

190. Lamas, *supra* note 27.

191. Morrison et al., *supra* note 183, at 1575.

192. *Id.*

193. Nachman, *supra* note 21, at 292–94 (arguing that lawyers must rely on a statutory basis and legal forms to assist clients while physicians follow hospital policy and medical orders); *id.* at 294 (“This duplicitous process is not only burdensome to the family and patient, it also creates countless opportunities for inconsistencies and ambiguities regarding end-of-life wishes, thus creating

legal approaches to end-of-life care are based on a faulty premise—patient/client absolute self-determination is the holy grail. The lack of success may be simple: end-of-life planning does not align with what people want at the end of their lives. The misplaced objective of upholding traditional autonomy and patient absolute control is incongruent with client values. Instead of insisting that end-of-life decision-making be defined by individual choice, the medical and legal communities should recognize that clients actually want a “private, family-centered affair.”¹⁹⁴

III. WHAT DYING PEOPLE WANT AT THE END OF THEIR LIVES

Many Americans support an individual’s right to die on their own terms in certain circumstances.¹⁹⁵ While promoting individual autonomy drives current medical and end-of-life decision-making, individuals do not value autonomy in the same way.¹⁹⁶ Even if a person identifies “a sense of control” as important, it is defined as shaping the care priorities rather than absolute authority.¹⁹⁷

What constitutes a “good death” is as unique as the individual. Many individuals “have priorities beyond being merely safe and living longer.”¹⁹⁸ Simply, dying people want their preferences respected.¹⁹⁹ Individuals have often identified the involvement and preparation of family and friends as critical to their dying process.²⁰⁰ Instead of deciding end-of-life choices alone, many want to share that process with loved ones.

unpredictability about the success of end-of-life choices.”); Kent W. Davidson, Chris Hackler, Delbra R. Caradine & Ronald S. McCord, *Physicians’ Attitudes on Advance Directives*, 262 J. AM. MED. ASS’N 2415, 2416 tbl.3 (1989) (noting that in an early study 73.4 percent of responding physicians agreed with the statement, “I would worry less about legal consequences of limiting treatment if I were following an advance directive”).

194. Fentiman, *supra* note 121, at 813; *see also* Boozang, *supra* note 134, at 550 (“The law’s exclusive focus on personal autonomy works great harm to the families of the dying by depriving them of meaningful participation in the death of their loved one.”).

195. TISDALE, *supra* note 137, at 39.

196. Winzelberg et al., *supra* note 173, at 1047.

197. *Id.* (quoting Peter A. Singer, Douglas K. Martin & Merrijoy Kelner, *Quality End-of-Life Care: Patients’ Perspectives*, 281 J. AM. MED. ASS’N 163, 163–68 (1999)).

198. GAWANDE, *supra* note 1, at 243.

199. *See* Emily A. Meier, Jarred V. Gallegos, Lori P. Montross-Thomas, Colin A. Depp, Scott A. Irwin & Dilip V. Jeste, *Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue*, 24 AM. J. GERIATRIC PSYCHIATRY 261, 261 (2016).

200. *See id.*; *see also* Barry & Edgman-Levitan, *supra* note 26, at 780.

A. “A Good Death”

The practice and process of death has changed dramatically over the last century. In past generations, people were more accustomed to witnessing death as it occurred at home with the dying individual surrounded by their loved ones.²⁰¹ It also happened at an earlier age from conditions that are now preventable with new medicine, innovations, and technology.²⁰² With life expectancy rates now circling seventy-seven years, many of us will live long past our earlier relatives.²⁰³ With longer life comes a greater likelihood that more of us will die from chronic diseases including heart disease, diabetes, and cancer.²⁰⁴ While advances in health care allow many to have longer and healthier lives, they can also wreak havoc on end-of-life care as treatment can continue long past the point of effectiveness.²⁰⁵ As patients live longer with various diseases, they face complicated medical data and complex choices.²⁰⁶ This can leave individuals isolated, overwhelmed, and left unable to make autonomous decisions.²⁰⁷

As delaying death and beating disease has increased, the medical community has been a willing accomplice as patients deny the inevitable.²⁰⁸ Emboldened by ongoing advances, doctors often see disease as something to “beat” and death as “failure.”²⁰⁹ Such language is fueled by medical training where doctors are focused on delaying death as long as possible and receive little training on how to talk about death.²¹⁰ As a result, patients receive more aggressive treatment at the end of life and less communication about what their death will or should look like.²¹¹

201. Dolgin, *supra* note 17, at 243–44.

202. Teneille R. Brown, *Denying Death*, 57 ARIZ. L. REV. 977, 980 (2015).

203. See *Life Expectancy*, CTR. FOR DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/nchs/fastats/life-expectancy.htm> [<https://perma.cc/G7KV-6Q58>] (last updated Feb. 7, 2023).

204. See Brown, *supra* note 202, at 981.

205. *Id.*; GAWANDE, *supra* note 1, at 6 (“[S]cientific advances have turned the processes of aging and dying into medical experiences, matters to be managed by health care professionals.”).

206. Ho, *supra* note 30, at 131.

207. *Id.*

208. Brown, *supra* note 202, at 981–82; Dolgin, *supra* note 17, at 244–46.

209. GAWANDE, *supra* note 1, at 7–8; *id.* at 9 (“Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need.”); see also Dolgin, *supra* note 17, at 246.

210. Dolgin, *supra* note 17, at 246–48.

211. See Brown, *supra* note 202, at 1012.

In 1997, the Institute of Medicine²¹² devised the phrase “a ‘good death’”²¹³ to represent “one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards.”²¹⁴ A “good death” has also been described as one where the individual’s “wishes were expressed and respected” and they had “a conversation about how they wanted to live toward the end.”²¹⁵ A “bad death,” by comparison, is characterized by “needless suffering” and “disregard for patient or family wishes or values.”²¹⁶

What a good death means to one person may vary greatly from the next person. For example, is it more important to be pain-free or conscious? Alone or surrounded by loved ones? Regardless of *what* someone chooses, the conversation has largely been about ensuring the dying person has autonomy *to* choose even if the choice is not what the medical provider believes is “best” or one that family members support.²¹⁷

A growing understanding of the importance of open dialogue about death and dying has led to a greater emphasis on preparation and planning.²¹⁸ This includes not only assisting the dying on their journey but also preparing those who provide care as well as those who are ultimately left behind. Traditional autonomy excludes the effects of dying on families, which contradicts the desire of individuals to consider the impact of their death on others.²¹⁹ Research demonstrates that patients do not choose traditional autonomy as the priority for end-of-life decision-making.²²⁰ In one study, chronically ill patients ranked “treatment choices

212. The Institute of Medicine is now known as the National Academy of Medicine. *About the National Academy of Medicine*, NAT’L ACAD. OF MED., <https://nam.edu/about-the-nam/> [<https://perma.cc/J5W9-6QVB>].

213. See Dolgin, *supra* note 17, at 240 (discussing the medieval use of “‘good’ death” to describe the vision a person receives warning them of their impending death).

214. COMM. ON CARE AT THE END OF LIFE, INST. OF MED. OF THE NAT’L ACADS., *APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE 4* (Marilyn J. Field & Christine K. Cassel eds., 1997) [hereinafter COMM. ON CARE].

215. Ellen Goodman, *How to Talk About Dying*, N.Y. TIMES (July 1, 2015, 6:45 AM), <https://archive.nytimes.com/opinionator.blogs.nytimes.com/2015/07/01/how-to-talk-about-dying/> [<https://perma.cc/UUC3-MB2H>].

216. COMM. ON CARE, *supra* note 214, at 4.

217. TISDALE, *supra* note 137, at 39–42.

218. See Abby Ellin, *‘Death Doulas’ Provide Aid at the End of the Life*, N.Y. TIMES (June 25, 2021), <https://www.nytimes.com/2021/06/24/well/doulas-death-end-of-life.html> (last visited Oct. 4, 2023).

219. See Winzelberg et al., *supra* note 173, at 1047.

220. *Id.*

followed” fifth out of nine attributes for quality of care.²²¹ This indicates that for many individuals the guiding force is not control but “being treated as a whole person.”²²²

B. To Include Loved Ones

Despite the affinity of many familial relationships, “the culture of death and dying has conspired to exclude the family from one of life’s most intimate moments.”²²³ In reality, dying patients view involving family members as “integral to their dying experience.”²²⁴ Coupled with rapid and continual advances in medical technology, more people will face complicated end-of-life treatment decisions.²²⁵ In the throes of a progressive illness or painful treatment, patients can feel overwhelmed, wrestling with complicated medical terms as they attempt to make medical decisions independently.²²⁶ Paradoxically, the current structure of autonomous decision-making leaves many feeling more isolated and helpless.²²⁷ At the end of their life, when they are contemplating their relationships with others, the emphasis is placed on the dying patient’s individual right to decide apart from the input and support of loved ones.²²⁸ This rigid process “deliberately ignores the truth of human interdependence and of our unavoidable need for human presence and care.”²²⁹

For many of us, dying will not be defined by our legal rights or struggle for autonomy, but by our relationships to and with others. While some argue these relationships constrain self-determination, others view shared decision-making as preferential.²³⁰ In fact, the largest study to examine

221. Karen E. Steinhauser, Nicholas A. Christakis, Elizabeth C. Clipp, Maya McNeilly, Lauren McIntyre & James A. Tulsky, *Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers*, 284 J. AM. MED. ASS’N 2476, 2481 (2000).

222. *Id.* at 2479.

223. Channick, *supra* note 12, at 638.

224. Singer et al., *supra* note 197, at 166.

225. Kathy L. Cerminara & Barbara A. Noah, *Removing Obstacles to a Peaceful Death*, 25 ELDER L.J. 197, 198 (2017).

226. *See* Channick, *supra* note 12, at 622; *see also* Brown, *supra* note 202, at 987–96 (arguing that many patients are in the dark about prognosis, treatment, and options due to the creation of “false hope” perpetrated by medical providers, and that patient ignorance about prognosis and the purpose of care leads to more treatment, in particular, more aggressive treatment).

227. Ho, *supra* note 30, at 131.

228. Singer et al., *supra* note 197, at 163.

229. INST. OF MED., *supra* note 25, at 125 (quoting THE PRESIDENT’S COUNCIL ON BIOETHICS, TAKING CARE: ETHICAL CAREGIVING IN OUR AGING SOCIETY, at xix (2005)).

230. *See* Channick, *supra* note 12, at 638; *see also* Brown, *supra* note 202, at 986 (discussing whether avoiding end-of-life discussions is due to a desire to encourage hope during treatment).

patient decision-making demonstrated that interventions that increase focus on autonomy do not necessarily lead to greater patient satisfaction at the end of life.²³¹ Rather than upholding individuality, patients want “the preservation of an overall sense of identity, agency and selfhood through connections with others.”²³² Family members and dear friends can be the constant reminder of a person’s rich history of experience and relationships which reinforce a person’s sense of self.²³³ A significant study more than two decades ago examined patient values and preferences at the end of life.²³⁴ The results revealed that when confronting death, people place great importance on a chance to say goodbye, be surrounded by loved ones, and receive loving care.²³⁵ Patients value repairing and strengthening existing relationships as well as building new support systems with other patients and medical providers.²³⁶ Importantly, study participants identified “not being a burden to family or society, [and] being able to help others” as principal factors.²³⁷

While patients want to remain in control of end-of-life medical decisions, they do not want to do it alone. Instead, they prefer to collaborate with both health care providers and loved ones.²³⁸ This approach varies by patient; for some, it means simply keeping family members well-informed of the medical situation, but for others, it means

231. See Alfred F. Connors, Jr., Neal V. Dawson, Norman A. Desbiens, William J. Fulkerson, Jr., Lee Goldman, William A. Knaus, Joanne Lynn & Robert K. Oye, et al., *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)*, 274 J. AM. MED. ASS’N 1591, 1591–92 (1995). One goal of the research was to examine the aftermath on patients and families of an acute incident followed by hospitalization. *Id.* It was assumed interventions aimed at enhancing patient participation in end-of-life decision-making would increase patient satisfaction. *Id.* at 1591. Instead, researchers discovered no difference in patient satisfaction between groups with or without intervention. *Id.* at 1596. Researchers identified that physicians not only did not know patient preferences for life-sustaining interventions, but they failed to communicate with both patients and families. See Channick, *supra* note 12, at 592–93 (explaining the “puzzling” outcomes from the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT), which followed 9,000 patients from 1989 to 1994). For a deeper discussion on SUPPORT, see MARILYN WEBB, *THE GOOD DEATH: THE NEW AMERICAN SEARCH TO RESHAPE THE END OF LIFE* 49 (1997).

232. Ho, *supra* note 30, at 131.

233. *Id.*

234. See Steinhauser et al., *supra* note 221, at 2476.

235. *Id.* at 2478–79.

236. Wright, *supra* note 28, at 1084.

237. Steinhauser et al., *supra* note 221, at 2479.

238. See Joan M. Teno, Virginia A. Casey, Lisa C. Welch & Susan Edgman-Levitan, *Patient-Focused, Family-Centered End-of-Life Medical Care: Views of the Guidelines and Bereaved Family Members*, 22 J. PAIN & SYMPTOM MGMT. 738, 745 (2001).

including family or even relinquishing decision-making to others.²³⁹ Some patients, in particular members of non-White groups, prefer to defer to loved ones throughout the end-of-life planning process.²⁴⁰ In a study, approximately one-third of terminal patients wanted their loved ones to have “complete leeway” to override the patient’s advance directive.²⁴¹ For some, it does not matter if the family member’s decision even accurately reflects patient choices.²⁴²

Surprisingly, some patients articulated that their preference was to communicate their wishes verbally to their chosen decision-maker.²⁴³ Even patients who viewed advance directives favorably did not want control over specific treatment options. Another study found many patients preferred to discuss their broad wishes or goals in a conversation rather than a document.²⁴⁴ Even some of those who had executed an advance directive would allow a surrogate to override their wishes if it was in the patient’s best interest.²⁴⁵ Focusing solely on autonomy and the right to make end-of-life decisions ignores the full picture of the needs of the dying. Instead of continuing to follow a rights-based model that is

239. See Wright, *supra* note 28, at 1085; see also Tuva Sandsdalen, Reidun Hov, Sevald Høye, Ingrid Rystedt & Bodil Wilde-Larsson, *Patients’ Preferences in Palliative Care: A Systematic Mixed Studies Review*, 29 *PALLIATIVE MED.* 399, 414 (2015). Studies reveal that terminal patients want to remain a voice in their care, but do not insist on specific control over each decision. See Singer et al., *supra* note 197, at 167.

240. Ho, *supra* note 30, at 130. A deeper examination of the intersection of the Western concept of autonomy with race, ethnicity, and culture is outside the scope of this Article. For a thoughtful discussion, see H. Russell Searight & Jennifer Gafford, *Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians*, 71 *AM. FAM. PHYSICIAN* 515, 516 (2005), and Jaelyn Portanova, Jennifer Ailshire, Catherine Perez, Anna Rahman & Susan Enguidanos, *Ethnic Differences in Advance Directive Completion and Care Preferences: What Has Changed in a Decade?*, 65 *J. AM. GERIATRICS SOC’Y* 1352, 1356 (2017) (stating that the low advance directive completion rates may also be tied to the notion that White individuals place a higher value on individual autonomy and end of life); Stephen C. Hines, Jacqueline J. Glover, Austin S. Babrow, Jean L. Holley, Laurie A. Badzek & Alvin H. Moss, *Improving Advance Care Planning by Accommodating Family Preferences*, 4 *J. PALLIATIVE MED.* 481, 482 (2001).

241. See Ashwini Sehgal, Alison Galbraith, Margaret Chesney, Patricia Schoenfeld, Gerald Charles & Bernard Lo, *How Strictly Do Dialysis Patients Want Their Advance Directives Followed?*, 267 *J. AM. MED. ASS’N* 59, 61 (1992). In another study, elder patients were characterized as “delegators” due to their choice to delegate decision-making choices. Merrijoy Kelner, *Activists and Delegators: Elderly Patients’ Preferences About Control at the End of Life*, 41 *SOC. SCI. & MED.* 537, 542 (1995).

242. Ho, *supra* note 30, at 132.

243. Baron, *supra* note 80, at 393 (citing Nikki Ayers Hawkins, Peter H. Ditto, Joseph H. Danks & William D. Smucker, *Micromanaging Death: Process Preferences, Values, and Goals in End-of-Life Medical Decision Making*, 45 *GERONTOLOGIST* 107, 113 (2005)).

244. *Id.* at 393; see also Ditto et al., *supra* note 140, at 498.

245. Sehgal et al., *supra* note 241, at 61–62 (finding that approximately one-third of patients preferred a surrogate to have “complete leeway” to override their advance directive).

ineffective and incongruent with client wishes, lawyers can expand their approach to client autonomy.

IV. END-OF LIFE COUNSELING FROM A RELATIONAL AUTONOMY PERSPECTIVE

*“The circumstances of medical decisionmaking at the end of life require some guiding principle other than everybody for themselves, because in these circumstances each person is inextricably bound to others.”*²⁴⁶

The conceptualization of autonomy as purely individualistic and exclusive of others may, paradoxically, infringe on a person’s autonomy rather than promote it.²⁴⁷ The rigid attachment to traditional autonomy creates a conflict between the ingrained commitment to self-determination and the fundamental belief in human connection to others.²⁴⁸ Instead of focusing solely on individual choice, the autonomy framework can be expanded to include “the relational nature of persons.”²⁴⁹

As the previous section highlighted, many dying individuals do not want or are unable to make end-of-life decisions on their own. The dominant autonomy framework contradicts patient preferences and reality to defend hardcore individualism by excluding the person’s loved ones.²⁵⁰ This next section refocuses end-of-life planning by advocating for attorneys to counsel clients based on relational autonomy rather than traditional autonomy. Relational autonomy redefines the “essence” of autonomy as the possibility of choosing “which of the myriad of influences in one’s life to make ‘one’s own.’”²⁵¹ The fallacy of defining autonomy solely by independence is that it limits a person’s sense of self, choices, and decision-making capability.²⁵² In fact, centering an individual within their important relationships allows one to “understand

246. Flick, *supra* note 14, at 1155 (emphasis added).

247. See Braudo-Bahat, *supra* note 33, at 114; Boozang, *supra* note 134, at 607 (“The consequence is often frustration of the very purposes the law intends to serve by depriving patients of what is often the final exercise of autonomy—delegation of decision-making to the family.”); Teresa Stanton Collett, *The Ethics of Intergenerational Representation*, 62 FORDHAM L. REV. 1453, 1462–63, 1469 (1994). See generally Thomas L. Shaffer, Essay, *The Legal Ethics of Radical Individualism*, 65 TEX. L. REV. 963 (1987).

248. See Fentiman, *supra* note 121, at 802.

249. Braudo-Bahat, *supra* note 33, at 129; see Roger B. Dworkin, *Medical Law and Ethics in the Post-Autonomy Age*, 68 IND. L.J. 727, 739 (1993).

250. See Boozang, *supra* note 134, at 557.

251. NEDELSKY, LAW’S RELATIONS, *supra* note 29, at 58.

252. See Burt, *supra* note 11, at 12.

how to foster their capacities, define and protect their rights, or promote their well-being.”²⁵³

Using this relational approach, lawyers can redirect the focal point from a purely rights-based process to one inclusive of a person’s supportive circle. It is consistent with client decision-making preferences that value relationships, collaboration, and shared decision-making. Applying a relational autonomy lens could prevent many of the challenges created by the reliance on traditional notions of autonomy. Instead of insisting that end-of-life planning be a private and personal matter, the inclusion of loved ones may lead to a death aligned with client values and wishes. Rather than leave surrogates to wonder about a loved one’s dying wishes, lawyers can engage clients and surrogates in a collaborative dialogue to better appreciate end-of-life goals. To counteract death anxiety and denial, meaningful client counseling can put a client at ease as they are supported in crafting the end-of-life care they choose.

A. *Overview of Relational Autonomy*

While feminist critiques of traditional autonomy²⁵⁴ challenge its theoretical, moral, and political underpinnings, most do not reject it all together.²⁵⁵ Instead, scholars argue to “reconceptualize and refigure” autonomy from a feminist perspective.²⁵⁶ Autonomy itself is not the problem, rather “the liberal tradition assigned great value to autonomy, articulated that value, and skewed our understanding of it.”²⁵⁷ Autonomy became synonymous with empowerment and protecting individual rights so as to prize separateness and devalue connection to others.²⁵⁸ The theory of “relational autonomy” redefines this hierarchy and asserts that autonomy and identity development should include relationships and

253. NEDELSKY, *LAW’S RELATIONS*, *supra* note 29, at 121.

254. Feminist scholars refer to “personal autonomy” or “liberalism.” Jennifer Nedelsky, *Reconceiving Autonomy: Sources, Thoughts and Possibilities*, 1 *YALE J.L. & FEMINISM* 7, 8 (1989) [hereinafter Nedelsky, *Autonomy*]. I will continue to use the phrase “traditional autonomy” for consistency. See Braudo-Bahat, *supra* note 33, at 113.

255. See Mackenzie & Stoljar, *supra* note 33, at 3, 5–12 (outlining five feminist critiques of autonomy—symbolic, metaphysical, care, postmodernist, and diversity—none of which advocate for an absolute repudiation).

256. *Id.* at 4.

257. NEDELSKY, *LAW’S RELATIONS*, *supra* note 29, at 44; see also Burt, *supra* note 11, at 10.

258. See NEDELSKY, *LAW’S RELATIONS*, *supra* note 29, at 44, 249.

connections.²⁵⁹ Those intimate and social relationships do not invalidate one's agency but instead "enable our autonomy."²⁶⁰

As the first scholar to consider relational autonomy through a feminist lens, Jennifer Nedelsky sought to reimagine the "making of one's own life and self."²⁶¹ While Nedelsky does not disregard autonomy altogether, Nedelsky does challenge the foundation of liberal individualism and viewing humans as separate from each other.²⁶² Nedelsky posits that the "basic value of autonomy is . . . central to feminism" and "[f]eminist theory must retain the value, while rejecting its liberal incarnation."²⁶³ Specifically, Nedelsky offers that traditional autonomy contains cherished values of freedom and self-determination that should not be discarded. Nedelsky criticizes the packaging of those values within a flawed framework that ignores the centrality of relationships when defining the self.²⁶⁴ Nedelsky acknowledges the oppression built into the literal concept of being defined by one's relationship to others and rejects this understanding. Nedelsky's solution is to reclaim autonomy and self-determination, by redefining the concept of "governed by one's own law."²⁶⁵

Part of the intrigue of Nedelsky's approach is the rejection of the individualistic interpretation of autonomous terms and reframing them from a relational perspective. As Nedelsky asserts, feminists aim to free women "to shape their own lives" and delineate themselves "rather than accepting the definition given by others."²⁶⁶ For example, rather than the historical definition of "independent" as "not subject to control by others,"²⁶⁷ Nedelsky interprets it as "the capacity to make decisions

259. Braudo-Bahat, *supra* note 33, at 113–14 (arguing an individualistic conception of "personhood" ignores that we "are embedded within networks of relations and relationships"). Said another way, it "provides an alternative understanding of autonomy that acknowledges the many social and contextual constraints and pressures that may be placed on choices while simultaneously recognizing that there is value in self-determination." Laufer-Ukeles, *supra* note 33, at 610; *see also* Mackenzie & Stoljar, *supra* note 33, at 4; NEDELSKY, *LAW'S RELATIONS*, *supra* note 29, at 3.

260. NEDELSKY, *LAW'S RELATIONS*, *supra* note 29, at 46.

261. Nedelsky, *Autonomy*, *supra* note 254, at 8.

262. *See* NEDELSKY, *LAW'S RELATIONS*, *supra* note 29, at 3.

263. Nedelsky, *Autonomy*, *supra* note 254, at 7.

264. *Id.* at 9.

265. *Id.* at 9–10.

266. NEDELSKY, *LAW'S RELATIONS*, *supra* note 29, at 121.

267. *Independent*, MERRIAM-WEBSTER DICTIONARY, <https://www.merriam-webster.com/dictionary/independent> [<https://perma.cc/YUE6-S84S>] (last updated Nov. 23, 2023) (defining "independent" as "not dependent: such as not subject to control by others: [self-governing]"); *Independence*, MERRIAM-WEBSTER DICTIONARY, <https://www.merriam-webster.com/dictionary/independence> [<https://perma.cc/59BA-XXPU>] (last updated Nov. 26, 2023) (defining "independence" as "the quality or state of being independent").

without being subject to anyone else's preferences, judgments, or choices."²⁶⁸ In fact, assuming the inclusion of relational considerations to be oppressive or disempowering is precisely the problem with traditional notions of autonomy: it prevents an individual from guiding their own thinking and identity formation.

Feminist, bioethicist, and medical scholars alike have advanced relational autonomy, considering it a preferable framework for achieving a more complete understanding of personhood.²⁶⁹ A purely individualistic view of autonomy that views humans as fully separate is incomplete.²⁷⁰ It is deficient because "human beings are *both* uniquely individual and essentially social creatures. The liberal individualist tradition has been not so much wrong as seriously and dangerously one-sided in its emphasis."²⁷¹ Instead, a relational definition of the self allows for a more flexible, dynamic view²⁷² that incorporates "the relationships through which each person interacts with others."²⁷³ When we see our essential identity as "constituted by relations" then our core belief and value system is situated within a focus on relationship.²⁷⁴ Selves "become who they are—their identities, their capacities, their desires—through the relationships in which they participate."²⁷⁵ Human beings have an inherent

268. NEDELSKY, LAW'S RELATIONS, *supra* note 29, at 142.

269. *See, e.g., id.* at 19 (asserting that our sense of self is shaped by our relationship with others); Carolyn Ells, Matthew R. Hunt & Jane Chambers-Evans, *Relational Autonomy as an Essential Component of Patient-Centered Care*, 4 INT'L J. FEMINIST APPROACHES TO BIOETHICS, 79, 80 (2011) (arguing that relational autonomy improves patient-centered care); Marilyn Friedman, *Autonomy, Social Disruption, and Women*, in RELATIONAL AUTONOMY, *supra* note 33, at 35, 36 (arguing for a "female-friendly account of autonomy" that includes social relationships); Dworkin, *supra* note 249, at 739 (suggesting reframing autonomy to "move away from the excesses of individual autonomy"); Jacqueline J. Glover, *Should Families Make Health Care Decisions?*, 53 MD. L. REV. 1158, 1165 (1994) ("Our very conception of who we are depends on the relationships in which we are involved."); Wright, *supra* note 28, at 1094 ("[R]elational autonomy is autonomy, just conceptualized in a way that accords with social reality." (emphasis omitted)); Channick, *supra* note 12, at 621 ("That so many factors converge at end-of-life renders the binary model of rights both inapt and unworkable.").

270. Braudo-Bahat, *supra* note 33, at 123; *see also* John Christman, *Autonomy, Independence, and Poverty-Related Welfare Policies*, 12 PUB. AFFS. Q. 383, 385–86 (1998) (arguing that every individual is inherently dependent on other people, institutions, and social groups which, in turn, contribute to the development of personal autonomy). Going even further, medical ethicist John Hardwig rejects a pure autonomy model and advocates for mandatory inclusion of family, arguing it is "irresponsible and wrong to exclude or fail to consider" family interests as the life and treatment of the patient cannot be "successfully isolated from the lives of the other members of his family." *See* John Hardwig, *What About the Family?*, 20 HASTINGS CTR. REP., Mar.–Apr. 1990, at 5, 6.

271. NEDELSKY, LAW'S RELATIONS, *supra* note 29, at 249.

272. *Id.* at 4.

273. *Id.* at 3.

274. *Id.* at 4.

275. *Id.*

need to situate themselves within a community to feel included, confident, and have a sense of belonging.²⁷⁶

Relational autonomy centers on “constructive relationships”—ones that develop and enhance a person’s core competencies.²⁷⁷ As individuals are embedded in a broader social system—whether family, friends, or larger community—that impacts their values, preferences, and attitudes.²⁷⁸ In a relational framework, the elements of decision-making—reflecting, deciding, choosing, planning—are collaborative activities, intertwined with others.²⁷⁹ These supportive relationships allow for autonomy growth “by observing others, leaning on them, learning from them, experiencing autonomy with them and practicing it with their help.”²⁸⁰ At its core, the theory of relational autonomy means that constructive relationships are crucial to self-determination, identity formation, and impact decision-making.²⁸¹

A relational approach focuses attention on “who gets to have a say in the formation of the norms that govern people’s lives.”²⁸² It can free us from the restrictions on identity, autonomy, and agency caused by isolation and separation. Ideals of independence and self-governance can be reimagined so that individuals are not constrained in making decisions that define their lives. Reclaiming and redefining autonomy as more inclusive and expansive will also lead to reshaping collective norms to benefit all individuals.²⁸³

B. Rationale for Integrating Relational Autonomy into End-of-Life Counseling

When applied to end-of-life counseling, the theory of relational autonomy will enable clients to make thoughtful decisions according to their choices, values, and identity.²⁸⁴ Centering client counseling within the “relational dimension of human experience” fundamentally alters a lawyer’s approach to the client, the client’s sense of self, and ultimately

276. See Braudo-Bahat, *supra* note 33, at 125.

277. *Id.* at 132; see also NEDELSKY, *Autonomy*, *supra* note 254, at 38–41, 46–49.

278. Braudo-Bahat, *supra* note 33, at 125.

279. Anne Donchin, *Autonomy and Interdependence: Quandaries in Genetic Decision Making*, in RELATIONAL AUTONOMY, *supra* note 33, at 236, 239.

280. Braudo-Bahat, *supra* note 33, at 132; see also NEDELSKY, *LAW’S RELATIONS*, *supra* note 29, at 55.

281. Braudo-Bahat, *supra* note 33, at 133.

282. NEDELSKY, *LAW’S RELATIONS*, *supra* note 29, at 365.

283. See *id.* at 43–44.

284. Wright, *supra* note 28, at 1082–85.

their decisions.²⁸⁵ It allows lawyers to advise clients that they can, and maybe should, consider the needs and interests of loved ones in their end-of-life decision-making.²⁸⁶

Adherence to traditional autonomy and strict notions of individualism in end-of-life care has been criticized by scholars across disciplines in favor of relational autonomy.²⁸⁷ Legal scholars have argued that the autonomy model is inadequate and “an inapt paradigm for death and dying.”²⁸⁸ Arguing the binary, rights-based model is unsuitable, some have advocated for the inclusion of family members in the dying decision-making process.²⁸⁹ One scholar, Professor Megan Wright, drawing on both legal and behavioral economics theories, offers “nudge[s]” to guide end-of-life law and policy.²⁹⁰ Relying on relational autonomy, Wright argues for a revision to current end-of-life legal structures, which are incongruent with people’s preferences to incorporate familial interests.²⁹¹ Specifically, Professor Wright suggests that health care providers should

285. NEDELSKY, LAW’S RELATIONS, *supra* note 29, at 3.

286. Wright, *supra* note 28, at 1113. Medical ethicists have discussed the involvement of family in medical decision-making and whether family interests should be considered. Professor John Hardwig argued that sometimes family members have a greater interest in patient treatment options and should even “override” patient interests. *See* Hardwig, *supra* note 270, at 5. While bioethicist Jeffrey Blustein does not support Hardwig’s proposal for equal decision-making, Blustein also asserts that current medical treatment improperly limits the family role and “both family members and patients suffer as a result.” Jeffrey Blustein, *The Family in Medical Decisionmaking*, 23 HASTING CTR. REP., May–June 1993, at 6, 11.

287. Carlos Gómez-Virseda, Yves de Maeseneer & Chris Gastmans, *Relational Autonomy: What Does It Mean and How Is It Used in End-of-Life Care? A Systematic Review of Argument-Based Ethics Literature*, BIOMED CENT. MED. ETHICS (Oct. 26, 2019) <https://bmcomedethics.biomedcentral.com/articles/10.1186/s12910-019-0417-3> (last visited Nov. 19, 2023); Winzelberg et al., *supra* note 173, at 1046–50; Ells et al., *supra* note 269, at 80; Ho, *supra* note 30, at 130.

288. Channick, *supra* note 12, at 584; *see also id.* at 620–23; *id.* at 631 (“[E]nd-of-life decision-making may not be suited to the binary, bright-line approach that the law tends to take.”); Wright, *supra* note 28, at 1093–119; Dworkin, *supra* note 249, at 739; Burt, *supra* note 11, at 10 (arguing it is best not to “override autonomous choice, but to remove this value from the center of attention and to recast our thinking about end of life care to promote different, though not necessarily inconsistent, goals”).

289. Channick, *supra* note 12, at 631, 637–38; *see also* Ho, *supra* note 30, at 133; Winzelberg et al., *supra* note 173, at 1047–48.

290. *See generally* Wright, *supra* note 28, at 1100–01, 1095–119 (examining end-of-life decision-making through the lens of behavior law and economics). Specifically, Wright uses “choice architecture” or “nudging” as an intentional decision-making scheme to counter a person’s cognitive biases. *Id.* at 1100–02. Wright utilizes the definition of “nudging” as “any aspect of the choice architecture that alters people’s behavior in a predictable way without forbidding any options or significantly changing their economic incentives.” *Id.* at 1101 (quoting RICHARD H. THALER & CASS R. SUNSTEIN, *NUDGE* 6 (rev ed. 2009)). Professor Wright applies this choice architecture theory to end-of-life decision-making law and policy.

291. *Id.* at 1100.

explicitly prod patients to consult with loved ones prior to deciding to forego life-sustaining treatment.²⁹² Additionally, Wright encourages revisions to advance directives to prime individuals to make end-of-life decisions mindful of their connections to others. These suggestions include restructuring the form to prioritize the chosen agent first before outlining treatment options, as well as adding the signature of the appointed agent to the advance directive. Wright reasons these changes would encourage discussions between patients and surrogates about end-of-life choices.²⁹³

While those suggestions are valuable, the aim of this Article is to center end-of-life lawyering in a relational autonomy context to enhance client decision-making. When lawyers counsel clients based purely on the traditional model of autonomy, this traditional concept is incomplete because it ignores dynamic aspects of the client's identity and decision-making process.²⁹⁴ Client counseling does not have to be restricted to insisting the client make death planning decisions alone based solely on their individual needs. A person's circle of connection is founded on intimacy, deep familiarity, and emotional connection.²⁹⁵ As such, familial relationships, friendships, and community provide mutual responsibility, shared values, and affinity for each other.²⁹⁶ This loyalty can create a perception and belief that "the family is part of the patient's identity, or even an extended part of the patient."²⁹⁷ A relational autonomy approach to end-of-life planning views the client's support network as nurturing and useful in assisting clients to make both meaningful and autonomous choices.²⁹⁸

1. *Aligning with Client Preferences*

Instead of continuing the fallacy that people make end-of-life decisions based exclusively on personal values, attorneys can recognize that most

292. *Id.* at 1105, 1107–12 (including other nudges like incorporating relational autonomy into surrogate decision-making standards, routinely utilizing shared decision-making between patients and physicians, and changing the default rule in physician aid in dying).

293. *Id.* at 1114–16.

294. See Braudo-Bahat, *supra* note 33, at 122.

295. Wright, *supra* note 28, at 1094.

296. Roy Gilbar & Nili Karako-Eyal, *Making Decisions About Artificial Ventilation at the End of Life: Does Law Affect Medical Practice*, 24 ELDER L.J. 293, 307 (2016).

297. *Id.*

298. Wright, *supra* note 28, at 1081–83.

people appreciate and rely on the input of loved ones.²⁹⁹ Lawyers can advise clients from the standpoint that all people are in a “network of connection and human interaction.”³⁰⁰ In fact, the Model Rules of Professional Conduct direct an attorney to “abide by a client’s decisions concerning the objectives of representation.”³⁰¹ This is not a directive to uphold client autonomy at all costs. Instead, it is an invitation for lawyers to reconceptualize client self-determination to be inclusive of others’ values.

Fundamentally, lawyers want to honor, support, and guide clients to the end-of-life plan they choose. This is the essence of client autonomy.³⁰² It is not uncommon for a lawyer to spend several hours with a client listening to their life story and the intimate details of their relationships and life experiences.³⁰³ Client interviewing includes discovering not just the factual choices of treatment but the reasoning behind those choices. In addition to delving deeply into client values, lawyers can consider the client’s years of relationships, interactions, and life experiences.³⁰⁴ It is critical to determine the personalities, behaviors, and challenges of family members in addition to that of the client. Proper interviewing probes beyond a client’s wish to “pull the plug” and explores family dynamics, sibling strife, or lack of trust among family members.³⁰⁵

Lawyers already incorporate consideration of a client’s spiritual beliefs or cultural values into client counseling.³⁰⁶ A relational approach expands client influences to include consideration of the impact of loved ones and friends on client interests and needs. It is typical for individuals to make other important life decisions with input from loved ones or community members. In fact, some argue “[i]n daily life, people defer to others, including friends and family members, on countless matters, and they are

299. Liz Blackler, *Compromised Autonomy: When Families Pressure Patients to Change Their Wishes*, 18 J. HOSPICE & PALLIATIVE NURSING 284, 288 (“[M]any patients reconsider previously held values, wishes, and preferences in the setting of broader effects on family. . . . Patients may decide to set aside personal wishes for the good of the family or as a means to maintain peace and harmony with loved ones. Given the interconnectedness present in many families, it is reasonable for patients to altruistically consider others when making serious medical decisions, even decisions in conflict with strongly held beliefs.”).

300. See Fentiman, *supra* note 121, at 841.

301. MODEL RULES OF PRO. CONDUCT r. 1.2(a) (AM. BAR ASS’N 2020); Bellard, *supra* note 15, at 808–09.

302. See Marla Lyn Mitchell-Cichon, *What Mom Would Have Wanted: Lessons Learned from an Elder Law Clinic About Achieving Clients’ Estate-Planning Goals*, 10 ELDER L.J. 289, 306–07 (2002).

303. See Orsatti, *supra* note 111, at 158.

304. Mitchell-Cichon, *supra* note 302, at 306–07.

305. Orsatti, *supra* note 111, at 159.

306. See de St. Aubin et al., *supra* note 95, at 260–61.

often better off as a result.”³⁰⁷ To be truly guided by client goals, lawyers must fully understand the complete picture of the client’s wishes.³⁰⁸ For some clients, counseling with consideration of familial interests will better meet their goals, including fulfilling their desire to consider the implication of their dying and death on loved ones.³⁰⁹

2. *Enhancing Client Decision-Making*

Inherent in being a good lawyer is the ability and skill to effectively counsel clients and guide decision-making.³¹⁰ Grounded in client-centered counseling, effective lawyers desire to understand the legal problem from “a client’s point of view” and appreciate that legal advice should be based on client values.³¹¹ Proponents of client-centered lawyering contend that it enhances client autonomy by empowering the client, not the lawyer, to make choices.³¹² When counseling is done well, “lawyers are conduits through which people can express their autonomy.”³¹³ Certainly, centering the client as the decision-maker is paramount, but lawyers can widen their view of client autonomy beyond individual independence.

The role of a lawyer has long included advising clients on non-legal matters.³¹⁴ It is codified in our ethical obligations that “a lawyer may refer not only to law but to other considerations such as moral, economic, social and political factors, that may be relevant to the client’s situation.”³¹⁵ Most lawyers would agree that a “genuine understanding of the client’s world and [their] unique perspective is essential for the attorney to define the client’s ‘interests’ in a meaningful way that approximates the true essence of the client.”³¹⁶ It is no longer innovative, but expected, that lawyers need to understand the emotional needs of clients, possess strong interpersonal

307. Wright, *supra* note 28, at 1133 (alteration in original) (quoting Cass R. Sunstein, *Foreword*, in *NUDGING HEALTH*, *supra* note 153, at xix).

308. Joseph A. Rosenberg, *Adapting Unitary Principles of Professional Responsibility to Unique Practice Contexts: A Reflective Model for Resolving Ethical Dilemmas in Elder Law*, 31 *LOY. U. CHI. L.J.* 403, 470 (2000).

309. *See* Wright, *supra* note 28, at 1113.

310. Mitchell-Cichon, *supra* note 302, at 296–97.

311. Robert D. Dinerstein, *Client-Centered Counseling: Reappraisal and Refinement*, 32 *ARIZ. L. REV.* 501, 504 (1990) (comparing client-centered counseling to the traditional model of counseling where the lawyer maintains more control and exercises significant influence); DAVID A. BINDER, PAUL BERGMAN & SUSAN C. PRICE, *LAWYERS AS COUNSELORS: A CLIENT-CENTERED APPROACH* 19, 21 (1991).

312. Dinerstein, *supra* note 311, at 512; Mitchell-Cichon, *supra* note 302, at 306.

313. Dinerstein, *supra* note 311, at 514.

314. Glover, *supra* note 135, at 447.

315. MODEL RULES OF PRO. CONDUCT r. 2.1 (AM. BAR ASS’N 2020).

316. Rosenberg, *supra* note 308, at 463.

skills, and develop a mutually respectful relationship.³¹⁷ Scholars have developed a variety of multi-disciplinary counseling models including Therapeutic Jurisprudence³¹⁸ and Relational Lawyering³¹⁹ that center the client's psychological well-being.³²⁰ Drawing from social work, psychology, and attachment theory, Relational Lawyering envisions that lawyers will understand a client's "extra-legal issues."³²¹ Lawyers who practice from a place of Relational Lawyering engage clients "in ways that affirm this mutuality and connection."³²²

Elder law attorneys are "uniquely positioned to sustain or improve the psychological health of their clients."³²³ Unlike medical providers who often have end-of-life conversations at the height of "the immediacy and gravity of incapacity,"³²⁴ for lawyers the timing can be less stressful. Years in advance of illness or injury, lawyers can engage clients in meaningful, thought-provoking dialogue when the client is not in the emotional process of dying. This gives lawyers room to discuss the potential legal consequences as well as the psychological aspects of dying.³²⁵ The solution is to demystify death, or at the very least, encourage

317. See Mitchell-Cichon, *supra* note 302, at 296–98.

318. Dennis P. Stolle, David B. Wexler, Bruce J. Winick & Edward A. Dauer, *Integrating Preventive Law and Therapeutic Jurisprudence: A Law and Psychology Based Approach to Lawyering*, 34 CAL. W. L. REV. 15, 17 (1997) (defining "therapeutic jurisprudence" as "an interdisciplinary approach to law that builds on the basic insight that law is a social force that has inevitable (if unintended) consequences for the mental health and psychological functioning of those it affects").

319. Susan L. Brooks & Robert G. Madden, *Relationship-Centered Lawyering: Social Science Theory for Transforming Legal Practice*, 78 REVISTA JURÍDICA UPR 23, 24 (2009) [hereinafter Brooks & Madden, *Relationship-Centered*]. Professor Brooks has since published several articles incorporating this theory into practice and legal pedagogy. See, e.g., Susan L. Brooks, *Mindful Engagement and Relational Lawyering*, 48 SW. L. REV. 267, 268 (2019) [hereinafter Brooks, *Mindful*] (using the framework of relational autonomy to more teach law students to be relational lawyers). Professors Brooks and Madden identify three competencies in their relationship-centered approach: (1) substantive theory related to human development; (2) principles of just and effective legal process; and (3) elements of interpersonal competence, including cultural competence and emotional intelligence. Susan L. Brooks & Robert G. Madden, *Epistemology and Ethics in Relationship-Centered Legal Education and Practice*, 56 N.Y. L. SCH. L. REV. 331, 342 (2012).

320. Winick, *supra* note 134, at 909–10.

321. Brooks & Madden, *Relationship-Centered*, *supra* note 319, at 25, 35–36 (basing lawyering on the four perspectives of Therapeutic Jurisprudence, Preventive Law, Restorative Justice, and Mediation).

322. Brooks, *Mindful*, *supra* note 319, at 271.

323. de St. Aubin et al., *supra* note 95, at 260.

324. Nola M. Ries, Maureen Douglas, Jessica Simon & Konrad Fassbender, *How Do Lawyers Assist Their Clients with Advance Care Planning? Findings from a Cross-Sectional Survey of Lawyers in Alberta*, 55 ALTA. L. REV. 683, 694 (2018).

325. de St. Aubin et al., *supra* note 95, at 260–61.

conversation about it.³²⁶ In addition to avoiding the task completely, death anxiety can diminish decision-making capability which may result in hasty, ill-prepared decisions.³²⁷

Valuing a client's desire to incorporate a more expansive view of selfhood as relational rather than individualistic can lead to more dynamic and creative thinking. Nedelsky theorizes that "human beings have the capacity to interact creatively with all the relationships that shape us—and thus to reshape, re-create, both the relationships and ourselves."³²⁸ Autonomy is improved and refined by our "capacity for creative interaction."³²⁹ These evolving interactions hone our skills of attention and responsiveness, insight and innovation. It requires transforming old patterns of functioning and creates new forms of engagement with others.³³⁰ The resulting outcome is to "make life dynamic and joyful, as well as generate the resilience to respond to extreme deprivation."³³¹

Familial relationships are often defined by a history of group discernment, collaboration, and shared decision-making. These intimate connections "shape the family's core values and beliefs and inform decision making."³³² Such interconnectedness may improve client decision-making including leading individuals to change their minds or reconsider their previously held beliefs.³³³ While some argue that family involvement may muddle individual decision-making, agency is actually preserved and refined under a reconceptualized relational view of autonomy.³³⁴ Understanding the client in a larger context of relationships will better prepare the client to make decisions about treatment or medical interventions.³³⁵ Individuals facing complex medical conditions and dizzying diagnoses may welcome the support and familiarity of loved ones when feeling confused and alone. The isolating approach of traditional autonomy may disempower those who face language or cultural barriers, or are new to Western medicine. Instead, family involvement would not only provide a comforting presence but preserve

326. "Let us deprive death of its strangeness Let us frequent it, let us get used to it." TISDALE, *supra* note 137, at 33 (quoting philosopher Michel de Montaigne).

327. Glover, *supra* note 135, at 437 (discussing that stressors, such as death anxiety, can impair decision-making by making usually well-reasoned people act impulsively).

328. NEDELSKY, LAW'S RELATIONS, *supra* note 29, at 47.

329. *Id.* at 46.

330. *Id.*

331. *Id.* at 48.

332. Wright, *supra* note 28, at 1132 (quoting Blackler, *supra* note 299, at 285).

333. *Id.* at 1113; *see also* Ho, *supra* note 30, at 131.

334. Ho, *supra* note 30, at 131.

335. *See* Wright, *supra* note 28, at 1115.

“an overall sense of identity, agency and selfhood” and promote a “sense of integrity and worth.”³³⁶

Promoting relational autonomy gives the client an opportunity to practice and develop skills that support autonomy. This includes cultivating an environment where the client recognizes and feels empowered by their values and sense of self.³³⁷ Often clients state what they believe they need in legal terms—an advance directive—rather than their goal of not being kept alive unnecessarily.³³⁸ At times the client’s stated goal is different from what they ultimately seem to want to accomplish. This is true of all legal work but is heightened when dealing with issues of death, which may produce fear, anxiety, hesitation, and disengagement.³³⁹ Not only is it necessary to fully understand the work to be done, but to ensure attorneys are preparing a client for the emotional process ahead. When clients are allowed to define what is meaningful in their life, and make future choices accordingly, those decisions are coherent and strengthened.³⁴⁰

C. Tools for Integrating Relational Autonomy into Client Counseling

Despite the recent push towards encouraging end-of-life discussions with healthcare providers, individuals instead choose to discuss matters with attorneys.³⁴¹ End-of-life planning is a complicated, emotionally charged, yet rich and meaningful area of practice. Clients no longer see the lawyer’s role solely as a legal document drafter but also as an advocate who encourages clients to discuss end-of-life wishes.³⁴² Lawyers representing older clients face complex ethical considerations as they navigate capacity issues, health care concerns, family relationships, and mortality.³⁴³ While many lawyers may not feel adequately trained to discuss end-of-life planning, those drawn to elder law are more suited to

336. Ho, *supra* note 30, at 131.

337. Ells et al., *supra* note 269, at 87.

338. Mitchell-Cichon, *supra* note 302, at 298 (discussing the difference between clients who express their goals “factually” versus clients who do so “legally”).

339. *Id.* at 297–301.

340. Ells et al., *supra* note 269, at 88–89.

341. Mercedes Bern-Klug & Elizabeth A. Byram, *Older Adults More Likely to Discuss Advance Care Plans with an Attorney than with a Physician*, 3 GERONTOLOGY & GERIATRICS MED. 1 (2017); Hooper et al., *supra* note 126, at 487; Ries et al., *supra* note 324, at 685 (discussing several studies that found participants more often discussed end-of-life wishes with a lawyer than a medical provider).

342. See Bern-Klug & Byram, *supra* note 341, at 3.

343. Rosenberg, *supra* note 308, at 405.

provide therapeutic support to clients who may experience death anxiety or worry.³⁴⁴

Even though ninety-two percent of Americans believe it is important to discuss their end-of-life care wishes, only thirty-two percent engage in the conversation.³⁴⁵ To prepare clients to create an end-of-life plan that accords with their wishes, lawyers can initiate a conversation that speaks to the client's underlying values and specific client goals.³⁴⁶ The lawyer can understand the emotional underpinnings of a client's motivation by valuing and introducing end-of-life discussions.³⁴⁷ Applying relational autonomy to lawyering incorporates our relationships with and responsibility to others into daily practice. For some, "the welfare of our loved ones may be more significant than the interests of any individual self in isolation."³⁴⁸

Incorporating relational autonomy into lawyering goes beyond a philosophical shift in mindset. The practice includes enhanced skill development in listening, communication, and questioning techniques.³⁴⁹ Lawyers can create conditions that expand the conversation beyond the individual client. This can include considering a wider array of interests as well as active involvement of the client's supportive relationships.³⁵⁰ Infusing this model into practice has several layers: advising clients—including loved ones in client meetings—and working with surrogates. As the next section discusses, family involvement may promote rather than disrupt client autonomy and well-being.³⁵¹

1. *Guiding Clients to Consider Interests of Loved Ones*

When choosing end-of-life treatment, some clients will want to consider their family's views as well as the impact of their choices on others.³⁵² As such, lawyers do a disservice when they fail to guide clients to consider the impact of their treatment decisions and death on their families and loved ones.³⁵³ Viewing the client through a relational autonomy lens, lawyers can approach client interviewing and counseling

344. Glover, *supra* note 135, at 447.

345. *About Us*, CONVERSATION PROJECT, INST. FOR HEALTHCARE IMPROVEMENT, <https://theconversationproject.org/about/> [<https://perma.cc/5F99-BFSF>].

346. Mitchell-Cichon, *supra* note 302, at 297–98.

347. *Id.*

348. Wright, *supra* note 28, at 1093; *see also* Ho, *supra* note 30, at 131.

349. Mitchell-Cichon, *supra* note 302, at 296.

350. *See* Ells et al., *supra* note 269, at 90–91.

351. Ho, *supra* note 30, at 131.

352. Glover, *supra* note 269, at 1165; *see* Rosenberg, *supra* note 308, at 472.

353. Bellard, *supra* note 15, at 814.

mindful of clients' larger circle of support. In discussing end-of-life planning, a lawyer's strategy can encompass the "relational dimensions of a person's autonomy."³⁵⁴ By engaging the client in a broader conversation of goals and values, including those of loved ones, the lawyer will assist the client in delving deeply into their goals and needs.³⁵⁵ Ultimately, this allows the client to create and fully develop a concrete plan for end-of-life care.

One initiative created a framework that can guide lawyers as they assist clients in drafting their end-of-life wishes.³⁵⁶ There are four core principles—exemplify, connect, engage, and steward—culminating in identifying "respect for what matters most to each individual."³⁵⁷ "Exemplify" is designed to encourage professionals to model meaningful conversations to demonstrate that "personal reflection and examination of our biases can be powerful ways to develop cultural curiosity and humility."³⁵⁸ Second, "connect" appreciates the integration of individuals with others and that a variety of factors "shape perspectives and interactions."³⁵⁹ The third element, "engage," is designed to encourage professionals to be "proactive" in eliciting information to fully understand all aspects of what matters most to the individual.³⁶⁰ Lastly, "steward" requires not only the collection of information but "handling that information with reverence."³⁶¹ Together, these principles lead to respectful end-of-life care decisions driven by the individual's goals, values, and preferences.³⁶²

This framework aligns with a relational autonomy approach to end-of-life counseling by prioritizing a client's individual values and preferences and recognizing their interconnectedness. For many clients, contemplating long-term disease with family involvement could decrease feelings of isolation and helplessness. Those supportive relationships

354. Wright, *supra* note 28, at 1115.

355. Orsatti, *supra* note 111, at 161; Mitchell-Cichon, *supra* note 302, at 297–98.

356. In 2012, the Institute for Healthcare Improvement and The Conversation Project created a public campaign to ensure end-of-life care is concordant with patient goals and wishes. See LAUGE SOKOL-HESSNER, ANGELA ZAMBEAUX, KEVIN LITTLE, LAUREN MACY, KATE LALLY & KELLY MCCUTCHEON ADAMS, INST. FOR HEALTHCARE IMPROVEMENT, "CONVERSATION READY": A FRAMEWORK FOR IMPROVING END-OF-LIFE CARE 4 (2d ed. 2019), <https://www.ihi.org/resources/white-papers/conversation-ready-framework-improving-end-life-care> (last visited Nov. 19, 2023).

357. *Id.* at 11.

358. *Id.*

359. *Id.*

360. *Id.* at 12.

361. *Id.*

362. *Id.* at 13.

provide stability, comfort, and a meaningful foundation of their identity and decision-making process.³⁶³ Consider this scenario: Kevin, age 79, comes to your office to complete estate planning documents. Kevin was recently diagnosed with Amyotrophic Lateral Sclerosis (ALS) and wants to discuss how to financially plan for possible long-term care, make end of life choices, and address the future of their husband, Jose. They have three children all living in different states. Kevin worries that Jose already feels overwhelmed and that their children will have a hard time watching Kevin weaken and die.

Many lawyers would focus this client interview on only Kevin's needs and their right to decide how they die. A lawyer might say, "End-of-life planning is all about you making decisions about how the end of your life will go. It is not about what your loved ones think or want for you. It is your choice, and your choice alone, to decide what treatment you do and do not want." While this is meant to empower the client to feel in control of the planning process, it may leave them feeling conflicted about the interests of their loved ones. Instead, using a relational lens and following the "Conversation Ready" principles allows a lawyer to encourage a client to acknowledge and honor their important relationships—not ignore or discard them as intrusive. This connection does not infringe on self-determination or agency but inspires "finding one's own law."³⁶⁴

The lawyer could advise Kevin, "You and Jose have made many important life decisions together and there is value in considering the impact on your husband as well as your children. I encourage you as a family to share all of your interests and values as you plan for specific treatment options. While it is critical that you share what is most important to you at the end of your life, it may also be important for you to consider how others will experience your death and being left behind." This sets the stage for Kevin to reflect and consider their own values as well as those of Jose and their children. The lawyer can better understand Kevin, their wishes, central relationships, and ultimately what matters most to Kevin at the end of their life.

2. *Including Loved Ones in Client Counseling*

For many clients, their decision-making is interwoven with and often dependent on the interests and needs of their loved ones.³⁶⁵ Despite this, it is common for attorneys to exclude family or friends and simply advise the client to share their completed estate planning documents with loved

363. Ho, *supra* note 30, at 131.

364. NEDELSKY, *LAW'S RELATIONS*, *supra* note 29, at 46.

365. See Collett, *supra* note 247, at 1454.

ones.³⁶⁶ This Article suggests that in addition to preparing clients to have these conversations with loved ones, attorneys should consider including surrogates and family members in some client meetings.³⁶⁷ The earlier family members are involved in planning, the more likely the wishes of the dying person will be known and followed.³⁶⁸ One scholar goes as far as to assert that, at times, the interests of the family members should override that of the patient.³⁶⁹ Others see it more as a balancing act with the patient having the final word.³⁷⁰

Attorneys who specialize in elder law and estate planning have significant experience in navigating family dynamics as it relates to client representation. It is common, and even suggested, for family members to be included in some form, whether as an observer, advocate, supporter, or client.³⁷¹ Grounded in a holistic, multidisciplinary approach, some elder law attorneys and academics alike have skirted, if not rejected, a strict traditional approach to representation. This has included representing multiple family members or the entire family.³⁷²

This Article does not advocate for lawyers to provide dual or family representation.³⁷³ While ethical rules do not insist on individual representation, it is the safest way to prevent conflicts of interest among family members.³⁷⁴ Instead, this Article advises lawyers to only represent

366. See Hooper et al., *supra* note 126, at 490.

367. Orsatti, *supra* note 111, at 162.

368. Wright, *supra* note 28, at 1090.

369. See Hardwig, *supra* note 270, at 5.

370. Bellard, *supra* note 15, at 815 (discussing views of Jacqueline Glover, who advocates for equality among parties, and James Nelson, who wants to balance interests but the final word remains with the patient).

371. Collett, *supra* note 247, at 1454; ASPIRATIONAL STANDARDS FOR THE PRACTICE OF ELDER LAW AND SPECIAL NEEDS LAW WITH COMMENTARIES, at A-3 (NAT'L ACAD. ELDER L. ATT'YS, 2d ed. 2017), <https://nysba.org/NYSBA/Meetings%20Department/2018%20Annual%20Meeting/Coursebooks/Elder%20Electronic%20Materials/01%20FINALapproved4.24.17.pdf> [<https://perma.cc/5J27-8FE3>].

372. See Stuart D. Zimring, *Ethical Issues in Representing Seniors, Persons with Disabilities and Their Families*, 4 NAELA J. 125, 127 (2008); Shaffer, *supra* note 247, at 968–72; Rosenberg, *supra* note 308, at 477.

373. See Collett, *supra* note 247, at 1453, 1466–84 (discussing four types of intergenerational representation—including representing both the elder and a family member or the family entity—that are outside the scope of this Article).

374. Collett, *supra* note 247, at 1466–67; Mark Falk, *Ethical Considerations in Representing the Elderly*, 36 S.D. L. REV. 54, 56–57 (1991); MODEL RULES OF PRO. CONDUCT r. 1.7(a) (AM. BAR ASS'N 2020) (providing that a lawyer shall not represent a client if it “involves a concurrent conflict of interest,” defined as representation “directly adverse to another,” or a “significant risk that the representation of one or more clients will be materially limited by the lawyer’s responsibilities to another client”); see also *id.* cmt. 28 (“[A] lawyer may not represent multiple parties to a negotiation whose interests are fundamentally antagonistic to each other, but common representation is

elders with the inclusion of loved ones as non-clients, third parties at the client's request. This allows for joint meetings between family members and the client after a clear discussion with the client regarding attorney ethical obligations and client consent.³⁷⁵ While representing only an elder provides greater protection against ethical mishaps relating to confidentiality and loyalty, it does not resolve all ethical issues.³⁷⁶ The lawyer must first identify and clarify that the elder is the client—not only because the lawyer is bound to follow the wishes of the client but because the Rules of Professional Conduct flow only from the attorney to the client.³⁷⁷ Additionally, individual representation ensures client confidences and private matters remain confidential.³⁷⁸

Attorneys need to be mindful that the presence of a third-party may not only lead to disclosed confidences but destruction of the attorney-client evidentiary privilege.³⁷⁹ This can be remedied by the lawyer meeting alone with the client first to discuss these issues, assessing the client's willingness to consent to disclosing information, and obtaining their consent to waive privilege.³⁸⁰ It can be a delicate balance to honor the client's relationship with the third party while protecting the integrity of the attorney-client privilege.³⁸¹ Including surrogates or family members in a deeper conversation with the client about values and wishes will provide future knowledge to loved ones if they are forced to decide.³⁸² The lawyer can take a leading role in facilitating family discussions similar to the questioning format and substance discussed above with Kevin and Jose. Family members will feel more certain about client treatment choices and are more likely to rely on the patient's values when making decisions later on their behalf.³⁸³ Importantly, the inclusion of loved ones early in the

permissible where the clients are generally aligned in interest even though there is some difference in interest among them.”).

375. See Bellard, *supra* note 15, at 820.

376. Collett, *supra* note 247, at 1458.

377. Bellard, *supra* note 15, at 820; *see also* Falk, *supra* note 374, at 58.

378. See Collett, *supra* note 247, at 1468; Falk, *supra* note 374, at 64–65. The requirement to protect confidences remains even if the client demonstrates diminished capacity, unless the lawyer “reasonably believes that the client has diminished capacity” and “is at risk of substantial physical, financial or other harm unless action is taken.” MODEL RULES OF PRO. CONDUCT r. 1.14(b) (AM. BAR ASS’N 2020).

379. Rosenberg, *supra* note 308, at 448.

380. One option is to create a form for the client to sign to ensure the client understands the duties of confidentiality and loyalty, as well as their right to waive confidentiality and attorney-client privilege. *See, e.g.,* Zimring, *supra* note 372, at 143–45 (providing examples of sample client letter and forms).

381. Rosenberg, *supra* note 308, at 449.

382. Orsatti, *supra* note 111, at 160.

383. Bellard, *supra* note 15, at 818.

planning process allows the family to practice working in unison before the client's death is imminent. For some, the dying process "offers important opportunities for growth, intimacy, reconciliation, and closure in relationships."³⁸⁴ It may also avoid unnecessary family strife or later court-involved proceedings.³⁸⁵

Lawyers can assist clients and loved ones as they prepare for difficult future decisions by addressing four interrelated areas: prolonging life, managing pain, quality of life, and end-of-life issues.³⁸⁶ Quality of life considers the individual's ability to communicate and engage in basic activities. End-of-life issues include whether to attempt certain treatment options such as a feeding tube or ventilator. Both intersect with whether to prolong life and how to address pain.³⁸⁷ Lawyers can engage a client and their family in discussions that include detailed questions and conversations around these four areas. Instead of just asking clients whether they want life-sustaining measures such as a feeding tube, the conversation can include specifics on what quality of life looks like and how much pain they are willing to endure when extending treatment.

Returning to Jose and Kevin, the lawyer can engage them in a conversation considering the interplay of quality of life, pain management, and treatment options. This includes more than whether Kevin wants life sustaining treatment and for how long. It involves delving into Kevin's values about what quality of life means and whether prolonging life is the most important consideration; whether Kevin can engage in daily activities, speak to loved ones, or have a likelihood of recovery.³⁸⁸ Instead of Kevin facing these painful decisions in isolation, Kevin can be buoyed by the support of their husband.

3. *Preparing Surrogates to Decide for Others*

As people live longer with chronic medical conditions, many which may render individuals incompetent, more medical decisions are made by someone other than the patient.³⁸⁹ Longer life spans bring a higher rate of dementia, intermittent incapacity, lengthy diseases, and an elongated dying process. Research reveals that as many as forty percent of hospital

384. Singer et al., *supra* note 197, at 167.

385. Orsatti, *supra* note 111, at 160.

386. See Eggenberger et al., *supra* note 92, at 17–18.

387. *Id.* at 18.

388. See *id.* at 19; *id.* at 20, tbl.2.

389. See Cholbi, *supra* note 167, at 201.

patients have cognitive impairments.³⁹⁰ Consequently, surrogates make approximately seventy-five percent of decisions for hospitalized patients.³⁹¹ Lawyers can play a part in assisting clients as they select the increasingly important role of surrogate, as well as preparing those surrogates for future decision-making.

Appointing a health care proxy or surrogate can lessen the impact of obstacles such as indecision, death anxiety, and unrealistic future hypotheticals. As patients begin to face death and the accompanying uncertainty and fear, family members can provide a source of calm and support.³⁹² A well-informed surrogate can speak for an incapacitated patient and “honor personal and family needs and deeply held values, traditions, and beliefs to best promote and protect the patient’s goals.”³⁹³ Not only do surrogates make critical treatment choices, but perhaps more importantly, their job “is to help write the script for the last stage of the principal’s life, guided by the values, character, and relationships of the principal.”³⁹⁴

In choosing a surrogate, many clients pick family members as they view them as critical participants in their death process.³⁹⁵ Family members are often the ones that know clients and their wishes best based on years of history, experiences, and familiarity.³⁹⁶ To improve surrogate decision-making, lawyers can advise clients to choose someone based on shared preferences and values.³⁹⁷ It may be useful to assist a client to move beyond choosing the person they “trust” and instead select someone who aligns with their stated end-of-life preferences. Rather than automatically accepting a loved one, lawyers can learn which family members are risk-takers, organized, dependable, or unpredictable.³⁹⁸ This, too, requires long conversations exploring family history, trauma, and long-forgotten

390. *Id.* at 203 (citing Jenna Fritsch, Sandra Petronio, Paul R. Helft & Alexia M. Torke, *Making Decisions for Hospitalized Older Adults: Ethical Factors Considered by Family Surrogates*, 24 J. CLINICAL ETHICS 125, 126 (2013)).

391. *Id.* (citing Elizabeth F. Hiltunen, Cynthia Medich, Susan Chase, Lynn Peterson & Lachlan Forrow, *Family Decision Making for End-of-Life Treatment: The SUPPORT Nurse Narratives*, 10 J. CLINICAL ETHICS 126, 127 (1999)).

392. Bellard, *supra* note 15, at 811.

393. Orsatti, *supra* note 111, at 165.

394. Charles P. Sabatino, *The Legal and Functional Status of the Medical Proxy: Suggestions for Statutory Reform*, 27 J.L. MED. & ETHICS 52, 54 (1999).

395. Singer et al., *supra* note 197, at 167.

396. Bellard, *supra* note 15, at 813 (stating that family members are often familiar with the person’s “entire life context” and possess “intimate knowledge of the patient’s values and view of medical care” (quoting Ezekiel J. Emanuel & Linda L. Emanuel, *Proxy Decision Making for Incompetent Patients: An Ethical and Empirical Analysis*, 267 J. AM. MED. ASS’N 2067, 2067 (1992))).

397. Kohn, *supra* note 153, at 301.

398. Orsatti, *supra* note 111, at 159.

incidents. Lawyers should know whether a surrogate lives near, whether they handle stress well, and whether they return phone calls.³⁹⁹ It is one thing to determine who the client deems “worthy” to inherit, and it is another to discover who the client believes is equipped to make emotionally fraught medical decisions.

Appointing a trusted agent in advance is beneficial as the agent “can adapt to changing medical circumstances and reevaluate decisions depending on the patient’s condition as the patient’s medical needs change.”⁴⁰⁰ In today’s technology-infused world, rarely is an end-of-life medical decision a binary one, like whether to remove life support or not.⁴⁰¹ Instead, it is multilayered and requires “treading into uncharted and unfamiliar territory *with* the patient—as the mental, emotional, and spiritual legs of the patient—to create or, more accurately, to co-create that ‘best possible’ future.”⁴⁰²

The premise of surrogate decision-making is that surrogates will make decisions aligned with the person’s preferences.⁴⁰³ They remain stuck in the entrenched belief that their task is to do exactly what the patient would choose. Research indicates that surrogates often get it wrong or at least they do not accurately predict patient preferences.⁴⁰⁴ Maybe surrogate reliability should not be the sole factor to measure success.⁴⁰⁵ This assumption is born out of the traditional autonomy model which does not include consideration of a multitude of values. In reality, patients do not expect a surrogate to follow a strict course but “are fairly forgiving about how surrogates exercise their autonomy so long as it is done conscientiously.”⁴⁰⁶ Instead of viewing surrogate selection as the person “*to do what I say,*” individuals may choose a surrogate because they decide, “*you are the one I want to decide.*”⁴⁰⁷

Research also indicates that surrogate decision-making is unreliable because surrogates lack of understanding of patient values and preferences.⁴⁰⁸ Instead of patients and surrogates making decisions when death is imminent, earlier grief counseling and death preparation may lead

399. *Id.*

400. *Id.* at 158.

401. *See* Shepherd, *supra* note 13, at 1717.

402. Sabatino, *supra* note 394, at 54 (emphasis added).

403. David Orentlicher, *The Limitations of Legislation*, 53 MD. L. REV. 1255, 1278 (1994).

404. Cholbi, *supra* note 167, at 204–06.

405. *See id.* at 214.

406. *Id.*

407. *Id.* at 215.

408. Hines et al., *supra* note 240, at 482.

to better outcomes.⁴⁰⁹ To counteract this unpreparedness, more frequent conversations between the patient and the surrogate leads to greater understanding by the surrogate.⁴¹⁰ Lawyers can greatly assist clients and surrogates in initiating thoughtful conversations early to discuss specific wishes of the client. This may also include assisting surrogates to fully understand their future role in compliance with state statutes and requirements.⁴¹¹ Often, surrogates must first follow client wishes before deciding based on the best interest standard.⁴¹² This provides an opening for the lawyer to initiate a conversation with the client and surrogate to discuss specific scenarios that may occur in the future. A well-informed surrogate armed with the knowledge of what the client actually wants leads to a more supportive and flexible substitute decision-maker.⁴¹³

The likelihood that others will step in and make decisions for incapacitated individuals is viewed as troubling or suspicious.⁴¹⁴ This binary proposition—the patient chooses or someone else does—assumes that patients want to be free from the influence or concern of others and that any input from third parties would diminish patient decision-making.⁴¹⁵ This faulty reasoning assumes that if a surrogate is involved in a medical decision, autonomy is discarded.⁴¹⁶ Instead, collaboration among family members may preserve “an overall sense of identity, agency and selfhood through connections with others.”⁴¹⁷

4. *Responding to Risks of Including Others*

There are, of course, individuals who do not want family members included in their end-of-life planning. Others do not have trusted people in their life to make these crucial decisions. Additional concerns include unsavory family or friends coercing vulnerable clients into unsafe decisions. Certainly, there are agency, hospital, and even judicial

409. Cholbi, *supra* note 167, at 214.

410. Hines et al., *supra* note 240, at 484 (“If the patient had more than five conversations with the surrogate about [end-of-life] treatment, the surrogate was more likely to report understanding patient’s wishes well.”).

411. Orsatti, *supra* note 111, at 160.

412. See Sabatino, *Evolution*, *supra* note 18, at 219.

413. Orsatti, *supra* note 111, at 160; see INST. OF MED., *supra* note 25, at 139 (“Health care agents who have been well prepared, who have the support of other family members and the clinical team, and who have been given some reasonable leeway in carrying out their role will be able to do so with fewer long-lasting negative effects.”).

414. See Flick, *supra* note 14, at 1131–32.

415. *Id.*

416. *Id.* at 1147–48 (“The fiction advanced is that the decision is what the patient would decide. Only the reality is that the patient is obliterated when the choice is made by another.”).

417. Ho, *supra* note 30, at 131.

protections in place to detect and prevent inappropriate decision-making.⁴¹⁸ This Article does not argue for mandatory inclusion of relatives but suggests lawyers recognize a client's desire to include loved ones in these intimate decisions. A more expansive approach to client selfhood and decision-making values can better serve clients and surrogates for the inevitable task of planning for death. Further, advance directives will still provide protection by allowing a client to exclude certain family members. Physicians and hospital administrators will still be present to ensure patient well-being remains intact. Lastly, court-appointed guardians or conservators can provide a level of oversight and protection.⁴¹⁹

From the beginning of end-of-life jurisprudence, the *Cruzan* Court expressed concern that the interests of family members may override patient rights: "Close family members may have a strong feeling—a feeling not at all ignoble or unworthy, but not entirely disinterested, either—that they do not wish to witness the continuation of life of a loved one which they regard as hopeless, meaningless, and even degrading."⁴²⁰ Notably, later in *Washington v. Glucksberg*,⁴²¹ the Supreme Court specifically relied on concern over ill-intentioned family members as a basis for rejecting the right to assisted suicide.⁴²² Rather than assume the worst of family members, it is more useful and realistic to adopt the approach taken by some lower courts. This approach involves designating family members as surrogates unless there is evidence that they are "motivated in their decision by anything other than love and concern."⁴²³ In fact, there is evidence that healthcare providers already turn to family members to be surrogates even when doing so may not be legally authorized.⁴²⁴

Some contend that relational autonomy is paternalistic as it is "attempting to protect patients against the potentially harmful consequences of their own stated preferences."⁴²⁵ It is contended that true autonomy allows people to make choices individually, even if they are

418. Boozang, *supra* note 134, at 609.

419. Wright, *supra* note 28, at 1131–33.

420. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 286 (1990).

421. 521 U.S. 702 (1997).

422. *Id.* at 732 ("If physician-assisted suicide were permitted, many might resort to it to spare their families the substantial financial burden of end-of-life health-care costs."); *see also* Channick, *supra* note 12, at 639.

423. *Barber v. Superior Ct.*, 147 Cal. App. 3d 1006, 1021 (1983).

424. Bellard, *supra* note 15, at 813; Glover, *supra* note 269, at 1158, 1162.

425. Wright, *supra* note 28, at 1124 (quoting TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 216 (7th ed. 2013)).

“bad” choices.⁴²⁶ This argument assumes that including others in decision-making is merely in the patient’s alleged “best interests” rather than upholding their actual choice.⁴²⁷ Critics of relational autonomy often assume that the interests of patient and family will conflict.⁴²⁸ They view the consideration of the patient’s illness on the family structure and functioning as irrelevant and marginalizing patient needs. This approach neglects the patient’s intersecting interests of personal concerns and interdependence on others.⁴²⁹

Critics argue paternalistic notions can impact surrogate decision-making when a surrogate chooses what is “best” for a patient.⁴³⁰ Some family members may be induced to overemphasize the patient’s family connection and minimize patient self-determination.⁴³¹ Some clients may want to include the voice of family, but do not want that voice to overpower their own. Family members can have different values relating to end-of-life, medical treatment, and death. Psychological stressors—including grief, guilt, shame, and denial—can impact familial decisions, even if the proxy knows the wishes of the patient’s family member.⁴³² Certainly, attorney advice should involve a thorough discussion of possible surrogate options, including the negative aspects of choosing family.⁴³³ When these stressors seem overwhelming for a client, the attorney may want to suggest that the client choose a non-family member. Choosing a close friend may allow the proxy to better align with patient wishes by removing years of familial conflict or potential conflicts of interest.⁴³⁴

5. *Guiding Clients Toward the Death They Choose*

Although the health care world is slowly adjusting, clients at the end of their life will likely face a medical community focused on ongoing treatment and cure.⁴³⁵ Instead of continuing to take “extreme measures to delay death,”⁴³⁶ patient preferences are for comfort measures rather than

426. *Id.*

427. *Id.* at 1124, 1126–27.

428. Ho, *supra* note 30, at 129.

429. *Id.* at 131.

430. Bellard, *supra* note 15, at 805.

431. *Id.* at 803.

432. *Id.* at 817.

433. *Id.* at 815–16.

434. *Id.* at 817.

435. Cerminara & Noah, *supra* note 225, at 215.

436. *Id.*

therapeutic, medical intervention.⁴³⁷ There is a role for lawyers to play as many people begin to move away from “isolated medicalized deaths” and towards a different experience.⁴³⁸ Counseling clients and surrogates through a relational lens allows lawyers to better prepare all involved to reflect on what a “good death” looks like in practical terms for that person. Lawyers can assist clients to gather as much information as possible, reflect on their personal values, and encourage clients to seek end-of-life care that is “patient-centered and family-oriented.”⁴³⁹

Relational autonomy allows for not only a shift in *how* lawyers communicate but also in *what* they relay to clients. It is common for lawyers to provide referrals for financial planners and accountants as clients contemplate death. Widening the circle to include end-of-life resources would provide clients with “a missing layer . . . the nonmedical resources which could help bring death back home.”⁴⁴⁰ This could include counseling clients about options other than aggressive medical intervention, such as hospice and palliative care, which better align with patient preferences. Lawyers can prepare clients to request treatment that supports their needs and wishes and incorporates familial support.⁴⁴¹

437. *Id.* at 200, 202 (citing Baohui Zhang, Alexi A. Wright, Haiden A. Huskamp, Matthew E. Nilsson, Matthew L. Maciejewski, Craig C. Earle, Susan D. Block, Paul K. Maciejewski & Holly G. Prigerson, *Health Care Costs in the Last Week of Life: Associations with End-of-Life Conversations*, 169 ARCHIVES INTERNAL MED. 480, 482–84 (2009)) (noting that one-third of medical expenses during the last year of life are actually spent in the last week of life, and aggressive interventions in the last month account for eighty percent of costs).

438. Taimie Bryant, *Aid-in-Dying Nonprofits*, 57 SAN DIEGO L. REV. 147, 214 (2020); see Deb Rawlings, Jennifer Tieman, Lauren Miller-Lewis, & Kate Swetenham, *What Role Do Death Doulas Play in End-of-Life Care? A Systematic Review*, 27 HEALTH & SOC. CARE CMTY., e82, e83 (2018); see also Ellin, *supra* note 218; Si Qi Yoong, Hongli Sam Goh & Hui Zhang, *Death Doulas as Supportive Companions in End-of-Life Care: A Scoping Review*, 36 PALLIATIVE MED. 795, 796 (2022). Nonprofit organizations also operate in this area. See *Our Vision, Mission, & Values*, INT’L END-OF-LIFE DOULA ASS’N, <https://inelda.org/who-we-are/our-vision-mission-values/> [<https://perma.cc/X4M4-3Z7L>] (stating that its mission is to “[e]ncourage the presence of end-of-life doulas by normalizing death, dying, and grief through conscientious education, and stewardship, and by fostering community and advocacy”); NAT’L END-OF-LIFE DOULA ALL. (NEDA), <https://www.nedalliance.org/> [<https://perma.cc/UE8D-HCL7>] (“NEDA’s mission is to influence positive changes in how people experience end of life by developing and advocating numerous efforts that improve access to a broad spectrum of holistic non-medical support provided by end-of-life doulas. Our goal is to elevate the role of end-of-life doulas to a position that is recognized, understood, utilized, and well-integrated into mainstream end-of-life care practices.”).

439. INST. OF MED., *supra* note 25, at 45–46 (defining “family” broadly to include “spouses, blood relatives, in-laws, step-relatives, fiancés, significant others, friends, caring neighbors, colleagues, fellow parishioners or congregants, and other people with a personal attachment to the person with advanced serious illness—in other words, the people ‘for whom it matters’”).

440. Rawlings et al., *supra* note 438, at 86 (citation omitted).

441. GAWANDE, *supra* note 1, at 128 (“For more than half a century now, we have treated the trials of sickness, aging, and morality as medical concerns. It’s been an experiment in social engineering,

“Palliative care” is broadly defined as “medical care intended to alleviate symptoms” at any stage of illness.⁴⁴² It is a more holistic, broad-reaching approach to illness with a focus on communication, patient goals, and quality of life.⁴⁴³ It is appropriate for both chronic and terminal illnesses and aims to address a variety of symptoms, including pain management, insomnia, nausea, and depression.⁴⁴⁴ The care is interdisciplinary as it includes not only medical providers, but social workers, naturopathic care, therapists, and religious entities.⁴⁴⁵ It has been referred to as “active total care,” which patients can receive while trying to live, as well as up until their last hour.⁴⁴⁶

At times, palliative care includes “decisional support” for patients as well as family members as they navigate advance directives, treatment goals, and options for care.⁴⁴⁷ Studies reveal that patients often improve when palliative care is added to their medical treatment.⁴⁴⁸ Patients report better well-being and better rates of satisfaction, as well as lower financial costs and fewer hospital stays.⁴⁴⁹ While medical providers may shy away from discussing palliative care or hospice as they remain attached to the goal of lengthening life, this avoidance is often not what patients want.⁴⁵⁰ “Hospice care,” which may include palliation of symptoms, family support, and a multi-disciplinary approach, is provided at the end of life.⁴⁵¹ A “death doula” or “end-of-life doula” guides a person who is

putting our fates in the hands of people valued more for their technical prowess than for their understanding of human needs.”).

442. Cerminara & Noah, *supra* note 225, at 202.

443. *Id.*

444. *Id.*

445. TISDALE, *supra* note 137, at 101.

446. *Id.* Hospice, which many people incorrectly equate with palliative care, is defined as care at end of life. While it may include palliative care, hospice is exclusively for terminal patients. See Cerminara & Noah, *supra* note 225, at 203–04.

447. Cerminara & Noah, *supra* note 225, at 203.

448. *Id.* at 204.

449. *Id.* at 207 (citing Glenn Gade, Ingrid Venohr, Douglas Conner, Kathleen McGrady, Jeffrey Beane, Robert H. Richardson, Marilyn P. Williams, Marcia Liberson, Mark Blum & Richard Della Penna, *Impact of an Inpatient Palliative Care Team: A Randomized Control Trial*, 11 J. PALLIATIVE MED. 180, 181–90 (2008)).

450. *Id.* at 220–21 (noting that when physicians introduced palliative care earlier it “reduced patients’ perceptions of ‘abrupt transitions which might be perceived as being abandoned’” (citing Marie Bakitas, Kathleen Doyle Lyons, Mark T. Hegel & Tim Ahles, *Oncologists’ Perspectives on Concurrent Palliative Care in a National Cancer Institute-Designated Comprehensive Cancer Center*, 11 PALLIATIVE & SUPPORT CARE 415, 420 (2013))).

451. Cerminara & Noah, *supra* note 225, at 203.

transitioning to death and their loved ones through the dying process.”⁴⁵² Death doulas assist the dying in a variety of ways, including comfort support, health care options, and even legal paperwork. They also assist families in navigating end-of-life medical issues, treatment options, and funeral planning.⁴⁵³

Lawyers can learn from palliative care specialists about how to counsel clients as they plan for the end of life. Clients struggle with contemplating hypothetical events in the distant future when they are currently healthy. Lawyers can assist clients to make more realistic decisions by helping them reflect on their values rather than treatment choices. For example, instead of asking, “What do you want loved ones to do when you are dying?,” lawyers can counsel clients to consider, “If time becomes short, what is most important to you?”⁴⁵⁴ Other questions suggested by palliative care specialists include: “What kinds of trade-offs are [you] willing to make?”⁴⁵⁵ or “How do [you] want to spend your time if your health worsens?”⁴⁵⁶ Could lawyers not ask these same questions?

Dying people want to be surrounded and supported by loved ones. Using a relational autonomy approach allows lawyers to dig deeper into client goals by viewing the client identity as more than self-interest.⁴⁵⁷ Considering the centrality of relationships in human lives will allow lawyers to assist a client to construct an end-of-life plan that accords with their desire to be surrounded by loved ones. This not only provides comfort and eases death anxiety but allows family members to process their grief as they consider life without their loved one. At the end of life, people want relief from their own suffering but also to relieve the suffering of others.

452. *What Is an End-of-Life Doula?*, INT’L END-OF-LIFE DOULA ASS’N, <https://inelda.org/about-doulas/what-is-a-doula> [<https://perma.cc/L2SQ-H6MD>] (last visited Oct. 7, 2023). The term “doula” is Greek meaning “woman’s servant” and has historically denoted a person supporting women during birth. See Yoong et al., *supra* note 438, at 796.

453. *What Is an End-of-Life Doula?*, *supra* note 452; Yoong et al., *supra* note 438, at 796.

454. GAWANDE, *supra* note 1, at 182.

455. *Id.* at 182–83. In a popular book about end-of-life medical care, Dr. Atul Gawande shared how they discuss treatment choices with a patient. *Id.* Gawande tells patients, “I need to understand how much you’re willing to go through to have a shot at being alive and what level of being alive is tolerable to you.” *Id.* at 183. In one example, the patient was contemplating a risky procedure that could result in substantial physical limitations. *Id.* The patient’s answer to the above question was, “Well, if I’m able to eat chocolate ice cream and watch football on TV, then I’m willing to go through a lot of pain if I have a shot at that.” *Id.*

456. *Id.*

457. NEDELSKY, LAW’S RELATIONS, *supra* note 29, at 4.

CONCLUSION

Approaching end-of-life counseling focused solely on an individual rights paradigm is overly restrictive and, paradoxically, out of alignment with the primary goal of many clients. Relational autonomy provides a multidimensional view of human experience and recognizes decision-making “involves acting and living according to one’s choices, values, and identity.”⁴⁵⁸ This theory does not necessarily reject traditional notions of independence, but seeks to enhance individual identity and agency through interdependence.⁴⁵⁹ It dismisses the idea that relationships are marginal or fringe rather than central to a person’s sense of self.⁴⁶⁰ Viewing people as focused purely on self-determination and disconnected from others paints an inadequate picture of autonomy.⁴⁶¹

It is not surprising that attorneys feel compelled to be guided solely by client rights and interests. Our profession is founded on the sacrosanct private relationship of attorney and client. Ethical rules prevent us, without client permission, from talking to family members or surrogates about confidential client information. Many lawyers hesitate to include third parties, even with consent, in client meetings because they are worried about ethical violations or professional consequences. But the knowledge that clients choose to include loved ones and consider their interests in the dying process should motivate lawyers to consider relational needs.

Lawyering through a relational autonomy lens frees the client to make decisions that value and honor their relational interests. While scholars argued that traditional autonomy would give the client more control and choice, expanding a sense of self—one that aligns with client values to include loved ones—will increase a client’s sense of control and choice. Choice and control do not mean deciding alone. Thoughtful, relationship-driven lawyering will enhance client decision-making as clients feel less isolated and able to make choices supported by loved ones. Surrogates included in client counseling will be ready to step in armed with the knowledge of client wishes. Centering end-of-life lawyering within the constellation of relationships will ensure meaningful client autonomy.

458. Friedman, *supra* note 269, at 37.

459. See NEDELSKY, LAW’S RELATIONS, *supra* note 29, at 5; Ho, *supra* note 30, at 131.

460. NEDELSKY, LAW’S RELATIONS, *supra* note 29, at 7.

461. Braudo-Bahat, *supra* note 33, at 123.

